



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) An evaluative review of the relationship between empathy and posttraumatic stress disorder; 2) Profiling the psychological training and support needs of oncology staff, and evaluating the effectiveness of clinical psychology provision in a general hospital department; 3) Investigating perceptions of disgust in older adult residential home residents.

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Research Portfolio Submitted in Part Fulfilment of the Requirements for the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

University of Bath
Department of Psychology

May 2014

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Abstracts

Main Research Project: Investigating perceptions of disgust in older adult residential home residents

As able-bodied people often become increasingly physically-dependent as they make the transition into older age, they may lose the ability to contain bodily fluids as they once had. Contact with bodily fluids is linked with feelings of disgust and, given the necessity of receiving assistance with intimate care activities, it has been suggested that self-focused disgust, and concerns over the disgust of others, may be important preoccupations in older people. This mixed-methods study therefore investigated feelings of disgust in fifty four physically-dependent older adults living in residential homes. Participants completed measures of disgust sensitivity, mood, and two new scales pertaining to feelings of self-disgust and perceived other-disgust when being assisted with intimate care activities. Results indicated that disgust was uncommon, although where present, self-disgust was related to perceptions of others' feelings of disgust and disgust sensitivity. These results were benchmarked against twenty one community-dwelling older adults, who reported believing they would feel significantly more disgusting if they were to start receiving assistance than those receiving assistance already did. Six of the residents who reported high levels of self-disgust also participated in semi-structured interviews. The thematic analysis was consistent with the quantitative results, with participants reporting that underlying protective factors, the use of strategies and carer characteristics reduced any feelings of disgust. The overall results are discussed with reference to the disgust literature, with recommendations being made for ways in which self-disgust can be minimised in residential homes.

Service Improvement Project: Profiling the psychological training and support needs of oncology staff, and evaluating the effectiveness of clinical psychology provision, in a general hospital department

The importance of training non-psychology healthcare professionals to offer psychological support to people with cancer is becoming increasingly recognised. Semi-structured interviews with five members of multidisciplinary oncology staff identified that training needs were primarily around communication skills, recognising and dealing with emotions, offering support and empathy, and self-care. Pre and post-training questionnaires developed with these themes in mind revealed that the Level 2 Training Programme workshops run in this network of hospitals are effective in increasing participants' levels of perceived knowledge and confidence across each of these domains. Recommendations are made for further enhancing this effectiveness.

Critical Literature Review: An evaluative review of the relationship between empathy and posttraumatic stress disorder

There is a small but growing body of evidence suggesting that PTSD may affect, and be affected by, an individual's level of empathy. This review identified and examined 20 papers investigating these relationships, exploring them with reference to the cognitive model of PTSD outlined by Ehlers and Clark (2000). The first finding suggested that level of empathy may either increase or decrease following traumatic experiences, depending upon the way in which an individual responds to their trauma. The second finding suggested that higher levels of empathy may either predispose or protect an individual from developing PTSD, depending upon their ability to use protective coping mechanisms. Finally, a third finding suggested that higher levels of empathy facilitate recovery from PTSD. It is recommended that empathy-enhancing work be included in PTSD treatment protocols, and that effective coping skills are taught to those likely to experience traumatic events.

Word count by components

Critical Literature Review: An evaluative review of the relationship between empathy and posttraumatic stress disorder	7219 words
Service Improvement Project: Profiling the psychological training and support needs of oncology staff, and evaluating the effectiveness of clinical psychology provision, in a general hospital department	4937 words
Main Research Project: Investigating perceptions of disgust in older adult residential home residents	5766 words
Executive summary of report: Investigating perceptions of disgust in older adult residential home residents	817 words
Connecting Narrative	2941 words

Total word count: 21680 words

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An evaluative review of the relationship between empathy and
posttraumatic stress disorder

Word count: 7219 (excluding figures and references)

September 2013

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This review is intended for submission to Psychological Bulletin, and has been written and formatted accordingly (please see Appendix A). This journal has been chosen as it publishes evaluative research reviews in scientific psychology, and accepts reports which summarise and draw conclusions from past research, with reports similar in nature to this one having therefore been published in this journal.

Abstract

There is a small but growing body of evidence suggesting that PTSD may affect, and be affected by, an individual's level of empathy. This review identified and examined 20 papers investigating these relationships, exploring them with reference to the cognitive model of PTSD outlined by Ehlers and Clark (2000). The first finding suggested that level of empathy may either increase or decrease following traumatic experiences, depending upon the way in which an individual responds to their trauma. The second finding suggested that higher levels of empathy may either predispose or protect an individual from developing PTSD, depending upon their ability to use protective coping mechanisms. Finally, a third finding suggested that higher levels of empathy facilitate recovery from PTSD. It is recommended that empathy-enhancing work be included in PTSD treatment protocols, and that effective coping skills are taught to those likely to experience traumatic events.

Keywords: Empathy, PTSD, Trauma

Introduction

Posttraumatic Stress Disorder (PTSD) is typically classified as an anxiety disorder which may develop following traumatic events such as assault, natural disasters and severe accidents. The symptoms include repeated and unwanted re-experiencing of the event (via, for instance, intrusive thoughts, ‘flashbacks’ and nightmares), hyperarousal and hypervigilance with an enhanced startle reaction, emotional numbing, detachment from other people and avoidance of stimuli (including thoughts) which could serve as reminders of the event (World Health Organisation; WHO, 1992). While many people experience at least some of these symptoms during the period of time immediately following a traumatic event, the symptoms may persist in a subgroup of people, often leading to significant impairments in social and occupational functioning. While the occurrence of either acute or continued trauma is deemed necessary for the onset of PTSD, research efforts have been made to identify factors specific to the individual which may either predispose them to, or protect them against, the onset of the condition, or affect the ease with which they recover from it. One growing area of research interest is concerned with the way in which interpersonal factors, including levels of empathy, affect, and are affected by, the development and maintenance of PTSD.

The cognitive model of PTSD

This review will examine relevant published literature relating to the relationship between empathy and PTSD, the findings of which will be synthesised and accounted for within the cognitive model of PTSD outlined by Ehlers and Clark (2000) (Figure 1). This model has been selected as it offers a clear and detailed account of the onset and maintenance of PTSD symptoms, and as it appears to be the model into which a possible role of empathy can best be incorporated (please see ‘*Empathy*’ section below for more detailed hypotheses).

As PTSD occurs as the result of memories for *past* events, Ehlers and Clark suggest that the way in which a past traumatic experience was processed may lead to a sense of serious *current* threat via two key processes: individual differences in the appraisal of the trauma and/or its consequences, and individual differences in the nature of the memory for the event and its link to other autobiographical memories. The authors suggest that individuals who develop persistent PTSD are unable to see the trauma as a time-limited event, perceiving it instead as having global negative implications for their future. In addition, it is proposed that, in persistent PTSD, the trauma memory itself is

poorly elaborated and not adequately contextually integrated (see also Brewin, Dalgleish, and Joseph (1996)), explaining the problems experienced with intentional recall, the ease with which physically similar cues trigger re-experiencing, the 'here and now' quality of these re-experiencings, and the absence of links to subsequent information which may provide reassurance.

The model proposes that these two processes (which lead to the sense of serious current threat) are themselves influenced by the way in which cognitive processing occurs during the traumatic event. Further, it is suggested that a range of background factors influence cognitive processing during the traumatic experience, as well as the nature of the trauma memory, the individual's appraisals of the trauma and/or its consequences, and the strategies used to control the PTSD symptoms and sense of current threat. For instance, it is suggested that previous experiences of trauma and pre-existing coping styles may affect the way in which the trauma is processed at the time, and that prior experiences and beliefs may affect the selection and implementation of cognitive and behavioural strategies used to control the PTSD symptoms.

The sense of current threat is accompanied by re-experiencing symptoms such as intrusions, as well as symptoms of arousal and strong emotional responses such as anxiety. Behavioural and cognitive responses (such as avoidance of related stimuli) which are meaningfully related to the individual's appraisal of the trauma and/or its consequences, as well as their general beliefs about how best to deal with the trauma, are also adopted. While the intention of these strategies is to reduce the sense of perceived threat and the distress caused in the short term, the model proposes that they are maladaptive as the long term consequence is that the disorder is maintained (as the strategies either directly produce PTSD symptoms, prevent changes in the negative appraisals of the trauma and/or its consequences, and/or prevent changes in the nature of the trauma memory itself). For instance, in an attempt to prevent further trauma, an individual who has experienced an assault may avoid people they consider to be similar to the attacker. This strategy may be unhelpful however as one possible consequence may be that the individual's sense of being a 'victim' who needs to protect themselves is maintained.

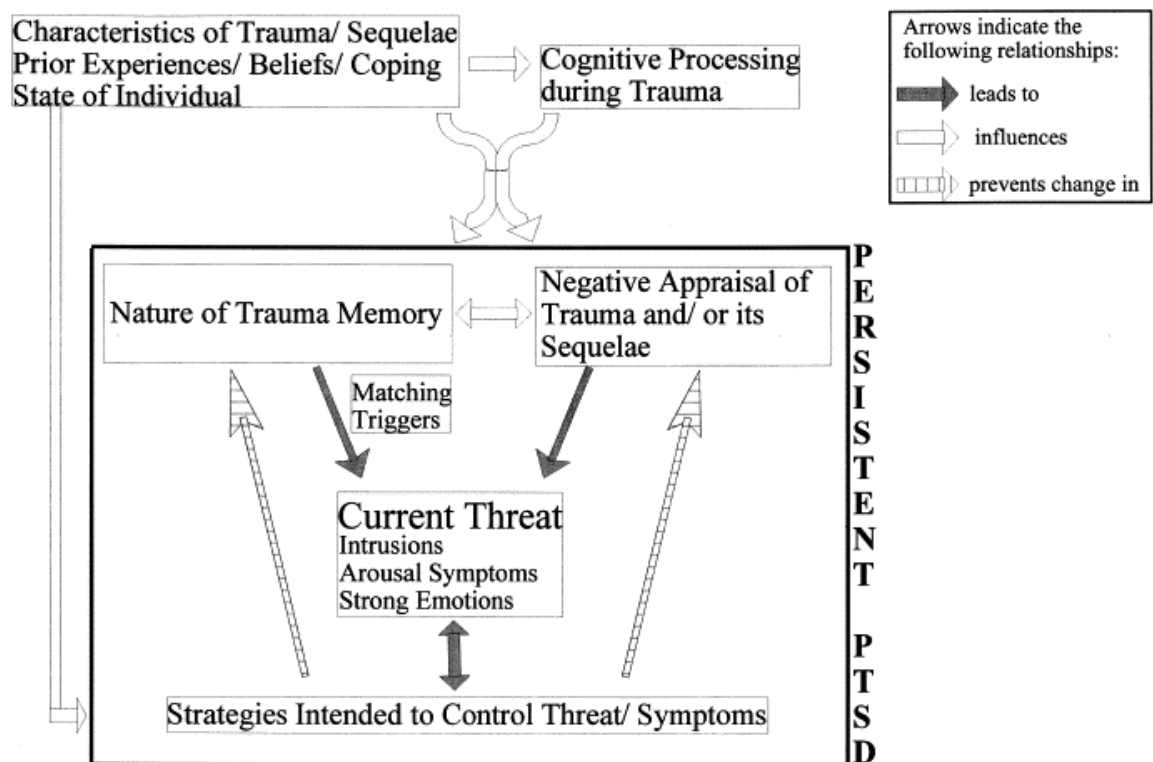


Figure 1. The cognitive model of PTSD (Ehlers & Clark, 2000)

Empathy

A number of definitions exist for the concept of ‘empathy’, the following of which will be used to define the term for the purposes of this review. Empathy has been simply defined as “*a vicarious experience of others’ emotions*” (Nietlisbach & Maercker, 2009, p. 389). More detailed definitions however include consideration of the cognitive components needed to infer and understand, and the affective components needed to share, the emotional experiences of others, in the absence of any direct emotional stimulation to the individual (e.g. Decety & Jackson, 2004; Gallese, 2003; Singer et al., 2006).

Considering the cognitive model of PTSD outlined above, empathy may be hypothesised as being a background factor which may influence cognitive processing during the traumatic experience and therefore also influence the nature of the trauma memory itself, as well as perhaps influencing the individual’s appraisals of the trauma and/or its consequences, and the strategies used to control PTSD symptoms. If so, the direction of influence will be important to establish (i.e. do higher levels of empathy predispose or protect an individual from developing PTSD?). It may also be hypothesised that the presence of PTSD symptoms may affect an individual’s level of

empathy, as a sense of current threat may lead to the activation of coping strategies which could include, for example, emotional distancing from, or to efforts to help, others. If so, again the direction of effect will be important to establish (i.e. do PTSD symptoms lead to an increase or decrease in levels of empathy?). Finally, it may be hypothesised that empathy could have a role in an individual's recovery from PTSD, as it may have an influence upon the appraisals made regarding self and others, and may also influence the coping strategies in which an individual with PTSD engages. If so, the direction of influence will again be important to establish (i.e. do higher levels of empathy aid or hinder recovery from PTSD?).

Rationale for this review

There appear to be conflicting conclusions drawn from the research examining the relationship between empathy and PTSD, necessitating the need for a review of the evidence within this area, and the integration of the findings within an appropriate psychological model. To the author's knowledge, there are currently no systematic reviews specifically exploring the relationship between PTSD and empathy. Alongside the ever-present occurrences of interpersonal victimisation, natural disasters and military conflict (all of which are known to confer a risk for the development of PTSD), this review is considered particularly timely in light of the roll-out of the Improving Access to Psychological Therapies programme. This scheme has resulted in more people with a diagnosis of PTSD being offered psychological therapies, necessitating a greater understanding of the development of this condition, and evidence based ways to treat it, both for practicing clinicians and those seeking treatment.

Aims of this review

This review aims to address the following key questions:

- Does PTSD (or significant traumatic experiences) affect an individual's level of empathy and, if so, in which direction?
- Do higher levels of empathy predispose or protect an individual from developing PTSD?
- Do higher levels of empathy aid or hinder recovery from PTSD?

Method

Definition of terms

To qualify for inclusion, the study populations must include a sample of people either with a diagnosis of PTSD, meeting the criteria for a diagnosis of PTSD, or having experienced significant trauma from which a diagnosis of PTSD may result. No limits will be set in terms of the age of participants, time since the experience of trauma or onset (or diagnosis) of PTSD. Similarly, no limits will be set in terms of the number or nature of the traumas experienced, or whether the traumatic incident was directly experienced or witnessed (as in vicarious traumatisation). Due to the high proportion of people with a diagnosis of PTSD experiencing co-morbid symptoms of low mood and other psychological difficulties, studies in which participants report co-morbidities will not be excluded. A number of measures of empathy exist and, as such, no restriction will be set in this review in terms of the measures used to assess empathy within the study participants.

Exclusion criteria for this review are as follows. Studies will not be included in this review if they are not available in English, due to a lack of available translation services. Studies will also not be included if they are published only as conference abstracts. This decision has been made as not enough information will be available from abstracts alone to meaningfully draw conclusions and integrate the study findings within the conclusions of this review. Further, studies will not be included in this review if they relate primarily to secondary traumatisation in therapists (and other health care professionals) working with people seeking treatment after the traumatic event. There is a large body of research within this area and it is beyond the scope of this review to include this in a meaningful way.

Identification of studies

This review will include relevant journal articles, theses and book chapters published up to September 2013. To ensure as inclusive a review as possible, no limit will be set in terms of participant numbers recruited into these studies or the inclusion of control groups. Relevant papers will be identified primarily via conducting searches using the following electronic databases: PsycINFO and PubMed. The following search terms will be entered into these databases: ‘PTSD’ “and” ‘empathy’, and ‘trauma’ “and” ‘empathy’. Results will first be screened for relevance based on the title of the paper, then secondarily based on the abstract, and then finally based on the full text article. See

Table 1 for the results of these searches, and Table 2 for a summary of their reported findings.

Results of database searches

Table 1. Results of search terms and identification of relevant papers.

Search engine	Search terms	Total returned	Excluded based on title*	Excluded based on abstract or full text	Relevant papers	Duplicates from previous searches	Included in review
PsycINFO	'PTSD' "and" 'empathy'	91	66	9	16	N/A	16
PubMed	'PTSD' "and" 'empathy'	119	91	22	6	4	2
PsycINFO	'trauma' "and" 'empathy'	502	450	38	14	12	2
PubMed	'trauma' "and" 'empathy'	353	318	31	4	4	0
Total papers included in review							20

* Four papers excluded as not available in English.

* The majority of exclusions being made due to papers reporting secondary traumatisation in therapists.

Results

Table 2. Summary of findings from included papers.

Paper authors	Number of participants	Direction of relationship	Strength of relationship
Nietlisbach and Maercker (2009)	<i>Review</i>	PTSD leads to lower empathy	<i>Qualitative</i>
Nietlisbach, Maercker, Rossler, and Haker (2010)	16 (vs 16 controls)	PTSD leads to higher empathy (which is suppressed)	IRI: $r = 0.26$; resonance: $r = 0.25$ & 0.33
Mazza, Giusti, et al. (2012)	20 (vs 30 controls)	PTSD leads to lower empathy	<i>Not specified</i>
Mazza, Catalucci, et al. (2012)	10 (vs 10 controls)	PTSD leads to lower empathy	<i>Not specified</i>
Millwood (2003)	32	Trauma leads to lower empathy	$r = -0.45$
Farrow et al. (2005)	13	PTSD leads to lower empathy	<i>Not specified</i>
Chaitin and Steinberg (2008)	<i>Review</i>	Trauma leads to lower empathy	<i>Qualitative</i>
Teten, Miller, Bailey, Dunn, and Kent (2008)	38	PTSD leads to lower empathy	$r = -0.13$
Frazier et al. (2013)	1528	Trauma leads to higher empathy	$r = 0.10$
Frazier, Conlon, Steger, Tashiro, and Glaser (2006)	135	Trauma leads to higher empathy	<i>Not specified</i>
Martin, McKean, and Veltkamp (1986)	53	PTSD leads to higher empathy	<i>Not specified</i>
Grevin (1996)	213	Higher empathy can be a risk or protective factor for PTSD	<i>Not specified</i>
Regehr, Goldberg, and Hughes (2002)	18	Lower empathy protects from trauma	<i>Qualitative</i>
Nelson (2013)	159	Higher empathy can be a risk for PTSD	$r = 0.17$
Feitelberg (2007)	129	Higher empathy can be a risk for PTSD	<i>Not specified</i>
Elliott (2007)	418	Higher empathy can be a protective factor for PTSD	$r = -0.13$
Woodward, Murrell, and Bettler (2005)	228	Higher empathy can be a risk for PTSD	<i>Not specified</i>
Sautter, Armelie, Glynn, and Wielt (2011)	<i>Review</i>	Higher empathy aids recovery from PTSD	<i>Qualitative</i>
Knetig (2013)	66	Higher empathy aids recovery from PTSD	$r = 0.24$
Kishon-Barash, Midlarsky, and Johnson (1999)	100	Higher empathy aids recovery from PTSD	$r = 0.48$

The effects of PTSD on levels of empathy

The first section of this review will focus upon the effects of traumatic experiences and PTSD upon levels of empathy.

Given the prevalence of relationship difficulties for people with PTSD (e.g. Cook, Riggs, Thompson, Coyne, & Sheikh, 2004), Nietlisbach and Maercker (2009) have reviewed the effects of interpersonal factors in the development and maintenance of PTSD. Within the umbrella term of ‘social cognition’, the authors identify empathy as being an affective element necessary for successful social interactions. The authors suggest that empathy may be impaired in people with PTSD due to them paying less attention to the environment (due to flashbacks and intrusions), emotional numbing (including loss of interest in activities, feelings of detachment from others and feelings of alienation and indifference), and avoidance (particularly avoidance of social situations and interactions). The authors call for more empirical research to address these potential relationships and they identify a need for prospective studies to examine the interactions between the components of social cognition (including empathy) and PTSD trajectories.

Nietlisbach, Maercker, Rossler, and Haker (2010) have addressed some of the issues raised in the review paper mentioned above. In particular, the authors investigated whether a sample of 16 participants with a diagnosis of PTSD (the majority of whom had experienced a ‘man-made trauma’ such as sexual assault) differed from a matched group of healthy controls on measures of empathy. The empathy measures used consisted of the Interpersonal Reactivity Index (IRI; Davis, 1980), an empathic resonance test (measuring social contagion such as propensity to yawn or laugh after watching another do so), and the Reading the Mind in the Eyes Test – Revised version (RMET; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) (used as a measure of the cognitive aspects of empathy). The results indicated that the PTSD group scored significantly lower than the control group on the empathic resonance tests and significantly higher on the ‘Personal Distress’ subscale of the IRI (which measures self-oriented responses to difficult situations of others). This is explained in terms of participants with PTSD unconsciously suppressing responses to contagious social information as a coping strategy in response to an aroused emotional system and heightened tendency to empathise with the difficulties experienced by others. The authors reduced a potential threat to validity by ensuring that differences in scores obtained on the empathic resonance test were not due to impairments in cognition more generally (measuring executive functioning in particular). No correlations were found between severity of PTSD symptoms and the scores obtained on the measures of

empathy. There were trends in the directions identified above however, and as the small sample size resulted in the power for the analysis being low, the authors suggest that these relationships be investigated further. In addition, while the group comparison findings for the RMET were not significant, there was again a trend for the PTSD group to show impairment, which lessened significantly with time since the trauma, implying a relationship between recovery from PTSD and an increase in levels of empathy (although this supposes that time since trauma and recovery are synonymous; research including a group of people who have recovered from PTSD would help in elaborating this further). It is important to note that, as the premorbid empathy levels of the PTSD group were not available, it cannot necessarily be concluded that the high IRI and low empathic resonance scores were a reaction to the trauma or PTSD symptoms (in that these may have been causal in the development of PTSD).

Emotional numbing is a common initial reaction to experiencing a traumatic event, and is a frequently experienced PTSD symptom (e.g. Ehlers & Clark, 2000). Mazza, Giusti, et al. (2012) investigated the presence of social cognition deficits (such as emotion recognition, theory of mind and empathy), and the association of these with emotional numbing, in a sample of 35 military police officers who were in Iraq from 2003 to 2006 for the 'Ancient Babylon' mission, and who were in Iraq during a major terrorist attack in An-Nasiriyah in April 2006. Twenty of the police officers met the criteria for a diagnosis of PTSD; the remaining 15 participants were recruited into one of the study's control groups, with a separate sample of 15 matched military police officers who had not participated in a military mission being recruited into a second control group. Alongside measures of other components of social cognition, empathy was measured using the Empathy Questionnaire (EQ; Baron-Cohen & Wheelwright, 2004). The results indicated that the PTSD group obtained a significantly lower score on the EQ than did either of the control groups. Further, when EQ score was included in a hierarchical regression model after other social cognition measures (such as measures of theory of mind), it was found to account for additional variance and to be a significant predictor of score obtained on the 'Avoidance and Numbing' subscale of the Davidson Trauma Scale (DTS; Davidson et al., 1997). The order in which variables were added into this regression model appears to have been appropriate, with the authors reporting having established the order of variables in accordance with Baron-Cohen's (1991) theoretical position on the evolutionary development of social cognition competence. Given these findings, the authors suggest that the emotional numbing frequently seen

within PTSD may result from impairments in social cognition, including empathy (in particular, in correctly perceiving and sharing other people's emotional experiences). However, given the suggestion by Nietlisbach and Maercker (2009) above that empathy may be impaired because of emotional numbing, further empirical work to establish the direction of causation would seem necessary. Further, as the nature of the analysis conducted was correlational, causation cannot be established, and the authors suggest future longitudinal research be conducted in order to establish whether social cognition deficits occur as a result of PTSD, or whether they serve as a risk factor for its development.

Using a small sample of 10 participants who developed PTSD following the L'Aquila earthquake in Italy in 2009, Mazza, Catalucci, et al. (2012) again demonstrated that levels of empathy, as measured by the EQ (Baron-Cohen & Wheelwright, 2004) were lower in their PTSD sample compared to a matched control group. There was also, again, a significant negative correlation between EQ score and score on the 'Avoidance and Numbing' subscale of the DTS (Davidson et al., 1997). This study therefore serves as a useful replication of the findings presented in Mazza, Giusti, et al. (2012) above, despite the small sample size recruited. Further support is also offered by Millwood (2003) who found, in a sample of 32 female survivors of childhood sexual abuse and their partners, that deficits in empathic accuracy were significantly correlated with levels of emotional numbing.

Attempts have been made to map the neurological basis of empathic judgements in those diagnosed with PTSD. Mazza, Catalucci, et al. (2012) identified that their sample of participants with PTSD had increased activation in the right insula and left amygdala, and reduced activation in the left lingual gyrus (areas believed to be involved in processing emotions), relative to healthy controls. In addition, Farrow et al. (2005) conducted a study in which 13 participants with PTSD underwent functional Magnetic Resonance Imaging (fMRI) while engaging in a variety of tasks, one of which was designed to evoke empathy. Participants engaged in this procedure both before and after completing a course of Cognitive Behavioural Therapy (CBT), with results indicating that the specific regions of the brain activated by empathy judgments changed with symptom resolution. In particular, there was a significant post therapy increase in activation in the left middle temporal gyrus, as would be expected in healthy controls. Interestingly however, participants' scores on the IRI (Davis, 1980) did not change

significantly from pre to post-therapy, suggesting that the changes observed on a neural basis did not necessarily coincide with changes in lived experience. While this study therefore offers support for the application of CBT for people diagnosed with PTSD, the suggestion that levels of empathy are affected by the resolution of PTSD symptoms must be interpreted with some caution.

Chaitin and Steinberg (2008), following their interview study with Jewish and Palestinian students, have asserted that being a victim of collective violence often leads to an inhibition of empathy towards others. One aspect of this study addressed what the authors term the 'intergenerational aspects' of victimisation, investigating the way in which the Holocaust may have had a negative impact on the expression of empathy among the descendants of victims (especially towards those considered 'enemies'). Chaitin and Steinberg (2008) argue that the self becomes seen as being a 'victim' while others are seen as 'perpetrators' or 'enemies'. This in turn is thought to then create continued animosity, with victims sometimes themselves becoming perpetrators, highlighting the importance of offering interventions which address these cognitive attributions and countering the inhibition of empathy demonstrated.

Similar conclusions have been drawn by Teten, Miller, Bailey, Dunn, and Kent (2008) from their study examining the relationship between empathy and alexithymia (sub-clinical inability to identify and describe emotions in the self) with impulsive (as opposed to pre-meditated) aggression in military veterans. Thirty eight participants (of whom 92% were male) from a larger population of veterans seeking treatment in a VA trauma recovery programme were recruited as they met the criteria for a diagnosis of PTSD and had committed at least one impulsive aggressive episode in the previous month. The majority of the sample were seeking treatment for combat-related trauma associated with service during the Vietnam War, although a small proportion had experienced other traumatic events such as sexual abuse. In stepwise multiple regressions, empathic deficits, as measured by the 'Empathic Concern' subscale of the IRI (Davis, 1980), significantly predicted verbal aggression, while alexithymia predicted impulsive aggression. It is important to note, however, that due to difficulties identifying non-aggressive participants from the VA trauma clinic, there was no control group in this study, meaning causality cannot necessarily be established.

In contrast to the aforementioned studies by Chaitin and Steinberg (2008) and Teten et al. (2008), research conducted by Frazier et al. (2013) found that, in a sample of 1528 participants, those who had experienced a greater number of lifetime traumas (such as the unexpected death of a loved one) reported engaging in more pro-social behaviours (which is relevant given that empathy is considered to be one of the central predictors of pro-social behaviour (e.g. Batson, 2010)). Having experienced a greater number of lifetime traumas explained additional variance in pro-social behaviour after accounting for other known correlates (including empathy, as measured by the 'Empathic Concern' subscale of the IRI (Davis, 1980)). Further, participants who had experienced a recent trauma reported engaging in more daily helping tasks than a matched control group and, within this recent trauma group (13% of whom met the criteria for a diagnosis of PTSD), engaging in pro-social behaviour was associated with greater well-being and perceived meaning in life. Although only a small proportion of the sample met the criteria for PTSD, engaging in more pro-social behaviours was also marginally correlated with a greater severity of PTSD symptoms, leading the authors to conclude that distress may motivate pro-social behaviour. As causality cannot be established however, these results may alternatively suggest that participants with a pre-existing propensity towards engaging in pro-social behaviours (and therefore, presumably, higher levels of empathy) were likely to experience higher levels of PTSD symptomatology following traumatic events. The authors were unable to measure whether engagement in pro-social activities *increased* following the occurrence of a recent trauma, or whether these were long standing patterns of behaviour; information which would be useful in establishing causality. Frazier, Conlon, Steger, Tashiro, and Glaser (2006) do however offer further evidence to support the occurrence of positive life changes following traumatic experiences, as the majority of a sample of 135 survivors of sexual assault identified increases in assertiveness, spirituality and empathy (especially concern for others people's suffering). These positive changes were further associated with fewer symptoms of depression, anxiety and PTSD, and greater life satisfaction.

In terms of feeling empathy for other victims of trauma, Martin, McKean, and Veltkamp (1986) investigated the effects of experiencing trauma for 53 police officers, 26% of whom met the criteria for a diagnosis of PTSD. Experiences of trauma within this group varied, but included incidents such as shooting someone or being shot, and witnessing the murder of civilians or colleagues. Seventy seven percent of the

participants who met the criteria for a diagnosis of PTSD described themselves as feeling a greater amount of empathy towards victims, compared to just 55% of participants who did not meet the criteria for a PTSD diagnosis. The authors propose that participants who did not meet the criteria for a diagnosis of PTSD may have developed coping strategies, such as distancing themselves from traumatic situations, which served to protect them, but also led to lower levels of empathy. As this study was correlational in design, it may be the case of course that levels of empathy did not *increase* for individuals with PTSD, but that these individuals had pre-existing higher levels of empathy which, in the absence of effective coping strategies (such as distancing themselves), facilitated the development of PTSD.

Considering the above studies, there appears to be disagreement within the literature over whether PTSD leads to a decrease (Farrow et al., 2005; Mazza, Catalucci, et al., 2012; Mazza, Giusti, et al., 2012; Nietlisbach & Maercker, 2009; Nietlisbach et al., 2010; Teten et al., 2008), or an increase (Martin et al., 1986; Nietlisbach et al., 2010), in levels of empathy, or whether having experienced traumatic events leads to a decrease (Chaitin & Steinberg, 2008; Millwood, 2003), or an increase (Frazier et al., 2006; Frazier et al., 2013), in levels of empathy. Considering these findings with reference to the cognitive model of PTSD (Ehlers & Clark, 2000), it is proposed that post-trauma increases in levels of empathy may increase an individual's sense of current threat (as they, and others, are more likely to be seen as vulnerable). This in turn leads to the activation of coping strategies intended to reduce the sense of threat. For some, more pro-social behaviours may be engaged in (which manifests as higher levels of empathy), while for others, attempts to emotionally distance the self from other people are employed (which then manifest as lower levels of empathy). As only linear analyses were conducted in each of the studies above, it may be that a quadratic relationship would fit the data (with PTSD resulting in either relatively high or relatively low levels of empathy), and it is suggested that future research investigate this possibility.

The role of empathy in the development of PTSD

The second section of this review will focus upon the role of empathy in either predisposing or protecting an individual from developing PTSD following a traumatic experience.

Exposure to traumatic events is commonly high for those employed within the emergency services. Accordingly, the results of a study by Grevin (1996) indicated that 20% of a sample of 120 experienced paramedics, and 22% of a sample of 93 student paramedics, met the criteria for a diagnosis of PTSD. Contrary to the author's hypothesis that levels of empathy would be lower in the experienced group, both the experienced and the trainee paramedics reported significantly lower levels of empathy (as measured by the Questionnaire Measure of Emotional Empathy (QMEE; Mehrabian & Epstein, 1972)), than the general population. There was no significant difference in empathy scores between the experienced and trainee groups, despite an average of approximately 10 years more emergency services experience in the experienced group. The relatively low levels of empathy in both groups was speculated to allow less personal involvement which would result in the paramedics being able to perform their duties more effectively, meaning that lower levels of empathy is a 'functionally adaptive mechanism' used to deal with the potentially traumatic nature of the work engaged in. Interestingly, the presence of low levels of empathy in the trainee population suggests that lower levels of empathy do not develop over time in response to a chronically stressful environment, but that this is a pre-existing trait within those who choose to pursue a career in the emergency services. While the author suggests that the lower levels of empathy may serve to protect against PTSD, there was only a weak positive correlation found between these variables. The author goes on to suggest however that the presence of a mediating variable, the ego defence mechanism of 'denial' (defined as 'refusing to acknowledge an experience or emotion'), as measured by the Lifestyle Index (Plutchik, Kellerman, & Conte, 1979) may explain this finding. Significant correlations were found between empathy and denial, and between PTSD symptoms and denial, such that denial may either predispose or inhibit a highly empathic person from developing PTSD. Grevin (1996) concludes that a highly empathic person who uses a lot of denial may be less likely to develop PTSD, while a highly empathic person who does not tend to use denial may be more likely to develop PTSD.

Similar findings have been reported by Regehr, Goldberg, and Hughes (2002). Their interview data with 18 paramedics revealed that, when experiencing traumatic incidents, a frequently employed coping strategy participants used was to cognitively distance themselves from the situation and attempt to shut down their own emotions. The authors stress that the use of these strategies do not necessarily represent an absence of

empathy, and given the findings of Grevin (1996), it may be suggested that the results of this study offer further support for the role of denial and distancing in mediating the relationship between empathy and PTSD.

Further support for the suggestion that high levels of empathy confer a risk for PTSD, unless coupled with high levels of ability to regulate emotions (through, for example, distancing and denial) can be found in Nelson (2013)'s study investigating the relationship between Emotional Intelligence (EI) and PTSD. In their sample of 159 American print journalists (who had experienced traumatic events such as encountering injured or dead children and witnessing motor vehicle accidents; 11% of whom met the criteria for a diagnosis of PTSD), higher levels of empathy (as measured by the Multidimensional Emotional Intelligence Assessment (MEIA; Tett, Fox, & Wang, 2005)) predicted greater severity of PTSD symptoms, while higher levels of self regulation (also measured by the MEIA) predicted lesser severity of PTSD symptoms. Entering these variables into a hierarchical regression model after demographic characteristics and trauma exposure, they were found to account for 15% of unique variance. The order in which variables were added into this regression model appears to have been appropriate, with the author reporting having established the order of variables in accordance with relevant literature and in line with their specific hypotheses.. As this study was correlational however, causation cannot necessarily be established, and it may be that the development of PTSD symptoms resulted in higher levels of empathy and lesser ability to regulate emotions.

The role of empathy within the development of PTSD in adolescents has also been investigated. A sample of 129 11 to 16 year olds living in Grand Cayman (56% of whom met the criteria for a diagnosis of PTSD) were recruited by Feitelberg (2007) 20 months after Hurricane Ivan had occurred in this area. In addition to a range of demographic and cultural factors, empathy (as measured by the California Healthy Kids Survey Module B (WestEd., 2006)) was found to add a small amount of unique variance in a hierarchical regression model (again, the order in which variables were added into this regression model appears to have been appropriate, with the author reporting having established the order of variables in accordance with relevant literature and in line with their specific hypotheses). Specifically, it was again found that higher levels of empathy predicted greater severity of PTSD scores (although, again, causality cannot necessarily be established due to the correlational nature of the analysis).

In contrast to the above studies suggesting that higher levels of empathy predispose an individual to develop PTSD, a study by Elliott (2007) found that higher levels of empathy (as measured by the Balanced Emotional Empathy Scale (BEES; Mehrabian, 1996)) served as a protective factor within a sample of 418 United States Army Soldiers who had recently returned from active service as part of 'Operation Iraqi Freedom'. The strength of the relationship between empathy and PTSD increased however when explained using a quadratic (curvilinear), rather than linear, relationship. The quadratic model suggested that participants who were either particularly low or particularly high in empathy were more likely to develop PTSD symptoms than those scoring in the moderate range for empathy (with the amount of variance in PTSD severity scores accounted for by empathy rising from 1.7% when using a linear model to 6% when using a quadratic model). Interestingly, higher levels of empathy also correlated significantly with experiencing greater distress when exposed to traumatic events. The author explains these findings in terms of participants with greater levels of empathy having greater general emotional development, resulting in them acknowledging greater levels of distress but having an increased ability to cope with this. It was also found that those high in empathy had significantly more social support, which itself was negatively correlated with PTSD. An explanation for the finding that those particularly high in empathy were also more likely to report more PTSD symptoms was not offered, however it may be that there is a point at which the greater coping abilities suggested to occur in those moderately high in empathy are overwhelmed by the distress experienced by those very high in empathy (meaning that this protective factor is removed and PTSD symptoms are more likely to develop). As causality cannot be established due to the correlational nature of the analyses in this study, the possibility that level of empathy either increased or decreased *following* traumatisation in the participants who reported a greater severity of PTSD symptoms cannot be ruled out.

In terms of vicarious traumatisation or Secondary Traumatic Stress Disorder (STSD; which presents with similar symptoms to PTSD but following *indirect* exposure to trauma), Woodward, Murrell, and Bettler (2005) argue that existing PTSD models are unable to adequately account for the presentation of symptoms as they do not include the role of empathy, which the authors term "*the primary factor that accounts for the impact of vicarious experience*" (p.3). In their sample of 228 American college students following the 9/11 terrorist attacks, emotional empathy, measured using the QMEE

(Mehrabian & Epstein, 1972), was demonstrated to be a key predictor of psychological distress and mediated the effects of interpersonal affiliation. The authors conclude that individuals high in empathy are more susceptible to STSD, although they note that, as the analyses conducted were correlational, the direction of causation cannot be established, in that higher levels of empathy may have resulted from the development of STSD symptoms.

The suggestion appears to be that high levels of empathy do have an effect on the likelihood of an individual developing PTSD (or STSD) following a traumatic experience. Interestingly, the results again suggest that this effect can be bi-directional, with high levels of empathy increasing risk in some and decreasing risk in others. The conclusions of the above studies suggest that general emotional development and the ability to use 'denial' or to effectively distance oneself from the traumatic experience may enable people who are high in empathy to protect themselves against PTSD. The implication of course is that those who are high in empathy but unable to do this are more likely to develop PTSD. Considering these findings within the cognitive model of PTSD (Ehlers & Clark, 2000), level of empathy, general emotional development, and tendency to use denial or distancing as a defence mechanism may well be important background personality factors which affect the way in which the trauma is processed at the time and the individual's later appraisals of the trauma. Specifically, high levels of empathy may lead to an increase in arousal (especially when witnessing harm to others) which may contribute to the memory disturbances seen within PTSD (Brewin et al., 1996), which in turn contribute to the development of PTSD symptoms such as reliving and a sense of current threat. The relationship between heightened arousal and memory disturbance may be reduced however by the use of the coping mechanisms described, such that the development of PTSD is less likely (with some of the findings suggesting that individuals high in empathy are better able to use these strategies and so less likely to develop PTSD than those with lower levels of empathy).

The role of empathy in the maintenance of, or recovery from, PTSD

The third section of this review will focus upon the role of empathy in either aiding or hindering an individual in recovering from PTSD following a traumatic experience.

Evidence for the importance of facilitating empathy in relation to PTSD treatment is provided in a paper by Sautter, Armelie, Glynn, and Wielt (2011) in which they describe a couple-based treatment for military personnel and their partners, entitled Structured Approach Therapy (SAT). Evidence suggests that successful recovery from PTSD is facilitated by social support with high levels of family stress being associated with poorer treatment outcomes (e.g. King, King, Fairbank, Keane, & Adams, 1998; Tarrier & Humphreys, 2003). The treatment approach outlined by Sautter et al. (2011) aims to reduce avoidance and emotional numbing within PTSD, with one of the two 'primary skill sets' trained in this approach being labelled 'empathic communication'. This refers to the ability to communicate with, and understand, another person (in this case a spouse or partner), including appreciating the other's perspective. Emotion awareness, identification and expression, using empathic communication, are also trained. It is proposed that the acquisition of these skills facilitate later exposure work and recollection sharing. Sautter et al. (2011) conclude by reporting that there is a limited amount of data supporting the utility of SAT (from just one study with six couples), but that a randomised clinical trial is currently underway.

Similar findings have been presented by Knetig (2013) who explored the relationships between social competence (including empathy), use of social support and PTSD symptoms in a sample of 66 military personnel. While a significant relationship between level of empathy (measured using the IRI, (Davis, 1980)) and PTSD was not found, the data did suggest that level of empathy was correlated with help-seeking behaviour and obtaining social support, which, in turn, were associated with a decrease in PTSD symptoms.

Further support for the role of empathy within recovery from PTSD is reported by Kishon-Barash, Midlarsky, and Johnson (1999) who recruited a sample of 100 military veterans (all of whom had a diagnosis of PTSD). Higher levels of empathy, as measured using the 'Empathic Concern' subscale of the IRI (Davis, 1980), was related to a greater intention to help others which, in turn, significantly predicted lower levels of PTSD symptomatology. It is important to note that causality cannot be established in this study, and so while the authors suggest that higher levels of empathy lead to improvements in symptoms, it may well be that lower levels of PTSD symptoms lead to higher levels of empathy. However, the conclusion that higher levels of empathy facilitate recovery is in line with those of Frazier et al. (2006) and Frazier et al. (2013)

discussed above, as they also concluded that higher levels of empathy led to an increase in altruism, which in turn led to a reduction in PTSD symptoms as well as greater wellbeing and life satisfaction.

The evidence presented, although limited, suggests that empathy is important in aiding recovery from PTSD. In particular, higher levels of empathy appear to facilitate help-seeking behaviours, healthy interpersonal relationships and altruistic behaviours, all of which are correlated with improvements in PTSD symptoms. It is suggested that improving empathic understanding and communication skills facilitate exposure work and recollection sharing which, according to the cognitive model outlined by Ehlers and Clark (2000), results in less avoidant behaviours and allows for the elaboration of trauma memories and their integration into autobiographical memory, which in turn reduces intrusive re-experiencing and the sense of current threat. Further, intentions to act in altruistic ways may influence the cognitive appraisals that the individual holds towards themselves, in that they may see themselves as worthwhile, capable and strong, rather than as a 'victim'. This again would serve to reduce their sense of current threat and the extent to which they engage in avoidant behaviours.

Discussion

This review aimed to investigate the relationship between levels of empathy and PTSD, with reference to the cognitive model of PTSD (Ehlers & Clark, 2000). With regard to the first specific question this review sought to address, whether levels of empathy increase or decrease following experiences of trauma, the results suggest that either may occur. It is suggested that experiences of trauma may lead to an increase in levels of empathy but that individuals may respond to this (and the resulting feelings of increased vulnerability) by either engaging in more pro-social behaviours (which manifests as higher levels of empathy), or attempting to emotionally distance themselves from others (which manifests as lower levels of empathy). With regard to the second specific question this review sought to address, whether higher levels of empathy predispose or protect an individual from developing PTSD, the results again suggest that either may be the case. It is suggested that high levels of empathy predispose individuals to develop PTSD (due to an increase in peri-traumatic arousal) unless they are able to effectively distance themselves from the traumatic experience (in which case they are less likely to develop PTSD than someone low in empathy). With regard to the third specific question

this review sought to address, whether higher levels of empathy aid or hinder recovery from PTSD, the results suggest that empathy is important in aiding recovery from PTSD. It is suggested that higher levels of empathy facilitate help-seeking behaviours, healthy interpersonal relationships and altruistic behaviours, which lead to a reduction in PTSD symptoms and greater general wellbeing.

Limitations

The main limitations of the papers included in this review include the often small sample sizes, differences in measures used to assess empathy, and the correlational nature of the (primarily linear) analyses conducted. Despite the differences in measures used, all measures were reported to have good reliability and validity, and to be measuring the same construct (empathy). The fact that the relationships discussed were all correlational however has meant that conclusions regarding causation cannot be established. That there exists a relationship between PTSD and empathy appears to be clear, however caution must be exercised when considering the way in which these factors interact. Finally, the fact that only linear analyses were conducted in the majority of the studies means that the possibility of non-linear relationships between PTSD and empathy (as is suggested by this review) has not been fully investigated.

The main limitations of this review itself include the relatively small number of papers which have been included, and the exclusion of papers which were not available in English (due to a lack of available translation services). As mentioned in this review, and by the authors of included papers, the amount of empirical work investigating the relationship between empathy and PTSD is scarce. However, this is a growing area, and it is recommended therefore that a review in this area be repeated in the future.

Implications for clinical practice and further research

There are some groups and professions within society for whom the likelihood of experiencing trauma is greater, such as those in emergency or military services. Given the finding that people who are high in empathy are more likely to develop PTSD in response to traumatic incidents if they are unable to effectively distance themselves or use ‘denial’, it is suggested that training which teaches these skills is provided before individuals are exposed to traumatic incidents (as described, for example, by Holaday and Smith (1995)).

Considering the finding that experiences of trauma can lead to a reduction in levels of empathy (and may therefore cause difficulties within social situations and relationships), it is suggested that information regarding this be included within psychoeducation work explaining the effects of PTSD to those seeking treatment. Further, as the importance of empathy-enhancing work for recovery from PTSD has been outlined, it is suggested that work to increase levels of empathy within intimate and family relationships (where appropriate), and work which encourages altruistic intentions, be included within treatment protocols for PTSD.

Throughout this review a recurring limitation of the studies included has been the inability for causation to be established. It is recommended that future research adopts longitudinal designs which allow for the measurement of levels of empathy prior to the experience of trauma. This could most easily be conducted with groups who are likely to be exposed to trauma within their professional roles (such as within military and emergency services). It is also suggested that non-linear relationships (in particular, quadratic relationships) between levels of empathy and PTSD be investigated, as it is suggested that these may better fit the factors under investigation. Specifically, the results of this review suggest that PTSD may lead to significantly greater levels of empathy in some individuals, but significantly lower levels in others, and it may be more likely to develop in individuals either particularly low or particularly high in empathy.

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Profiling the psychological training and support needs of oncology staff,
and evaluating the effectiveness of clinical psychology provision, in a
general hospital department

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This review is intended for submission to the Journal of Psychosocial Oncology, and has been written and formatted accordingly (please see Appendix B). This journal has been chosen as it publishes research relating to the provision of psychosocial care for cancer patients, and accepts reports investigating the psychosocial needs of both cancer patients and hospital staff, with reports similar in nature to this one having therefore been published in this journal.

Abstract

The importance of training non-psychology healthcare professionals to offer psychological support to people with cancer is becoming increasingly recognised. Semi-structured interviews with five members of multidisciplinary oncology staff identified that training needs were primarily around communication skills, recognising and dealing with emotions, offering support and empathy, and self-care. Pre and post-training questionnaires developed with these themes in mind revealed that the Level 2 Training Programme workshops run in this network of hospitals are effective in increasing participants' levels of perceived knowledge and confidence across each of these domains. Recommendations are made for further enhancing this effectiveness.

Keywords: Oncology, Psychosocial skills training, Level 2 Training Programme

Introduction

It is estimated that there are approximately two million people living with or beyond cancer in the UK, with this figure being predicted to rise by more than 3% a year (Maddams et al., 2009). As well as the physical effects of cancer and its treatment, the psychological effects can vary widely depending upon a number of factors, such as location of cancer (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), stage and spread of disease, prognosis for recovery, and patient age and life stage (Kornblith, 1998; Spencer, Carver, & Price, 1998). It is reported that significantly elevated levels of psychological distress tend to be diagnosed in approximately 35% of patients (Zabora et al., 2001), although it is likely that conditions such as depression are underdiagnosed in this group, suggesting that this figure could well be significantly higher (Aukst-Margetić, Jakovljević, & Margetić, 2002), with some studies reporting significant levels of distress being found in up to 77% of patients (Mertz et al., 2012). In addition, cancer survivors have been shown to be more likely to experience clinically significant increases in depression and anxiety compared to non-cancer control groups, with these worsening over time if left untreated (Schumacher et al., 2013). Overall, psychological distress within cancer patients has been recognised as having significant effects upon cognitive and emotional functioning and quality of life, and may lead to increased healthcare costs (Clark et al., 2012).

Given the prevalence of psychological distress in patients diagnosed with cancer, the ethical imperative of psychological screening has been outlined, and it has been suggested that empirically-based psychological treatments be offered as necessary (Carlson & Bultz, 2003). Accordingly, brief screening tools such as the Distress Thermometer have been demonstrated to be efficient and effective in identifying people with cancer who are distressed and are likely to accept psychological support (Ryan, Gallagher, Wright, & Cassidy, 2012). There is also evidence suggesting that the way in which a patient copes with their initial cancer diagnosis has a significant effect on their psychological adjustment years later (Hack & Degner, 2004). Specifically, patients who are depressed following diagnosis, and who respond to their diagnosis with 'cognitive avoidance' tend to have poorer adjustment after three years, leading authors to suggest that psychological interventions aiming to foster an approach-based coping style and positive well-being should be offered to patients following a cancer diagnosis if necessary.

In terms of psychological screening and interventions offered to people diagnosed with cancer, Cognitive Behavioural Therapy (CBT) in particular has been demonstrated to reduce distress, depression, anxiety and PTSD symptoms, increase optimism, and improve quality of life and adjustment to a cancer diagnosis (Antoni et al., 2006; Antoni et al., 2001; Groarke, Curtis, & Kerin, 2013; Kangas, Milross, Taylor, & Bryant, 2013; McLoone, Menzies, Meiser, Mann, & Kasparian, 2013; Nenova et al., 2013; Osborn, Demoncada, & Feuerstein, 2006; Tatrow & Montgomery, 2006; Taylor, 1983). In addition, psychoeducational interventions facilitating improvements in self-efficacy and self-esteem, and reductions in intrusive thoughts, appear to be beneficial and can mediate the effects of other psychological interventions and result in better symptom management (Budin et al., 2008; Chan, Richardson, & Richardson, 2012; Faller & Herschbach, 2011; Jones et al., 2013; McLoone et al., 2013).

In addition to the literature outlined above, The Manual for Cancer Services: Psychological Support Measures (National Cancer Action Team; NCAT, 2011) states that psychological support for people with cancer and their carers may be needed at any point along the cancer pathway and may be delivered by a variety of healthcare professionals within an acute hospital setting. This document outlines a four-level model of care for psychological support services, with Level 1 referring to basic psychological care which can be provided by all health and social care staff without requiring further specific training, through to Level 3 which refers to counsellors and mental health nurses, and Level 4 which refers to mental health specialists (such as psychiatrists and clinical psychologists), providing specialised psychological interventions. Level 2 psychological care involves screening for psychological distress and implementing basic psychological support and techniques, with additional training being provided to health and social care professionals to enable them to work at this level. This is in line with 'The Cancer Reform Strategy' (sections 5.33-5.36; Department of Health, 2007) which states that Level 2 psychological support should include effective information giving, compassionate communication, general psychological support, and psychological interventions such as anxiety management and problem solving.

The additional training provided at Level 2 comprises attendance on a National Advanced Communication Skills Training course and participation in a network based training programme which covers basic psychological screening, assessment and

intervention skills. The exact content of this latter training aspect is not specified in the Manual for Cancer Services (NCAT, 2011), with networks being enabled to design their own training programmes in accordance with the guidelines provided.

Local context: The Level 2 Training Programme workshop

The local NHS hospital trust provides Level 2 Training Programme workshops to multidisciplinary (MDT) members of oncology staff, both from within the trust and the local network. These workshops comprise eight sessions held over two full days and are facilitated by a clinical psychologist working within the hospital trust. The content of the workshops was devised by a subgroup of clinical psychologists from different hospitals in the local network. A day was devoted to discussing clinical expertise in this area and reviewing relevant literature, including the content of Level 2 Training Programme workshops from other networks across the country. The structure of the workshops has been decided as follows:

- Session 1 – introduction; and psychology of cancer care
- Session 2 – psychological distress, stress and anxiety 1; and mechanisms and processes
- Session 3 – clinical impact of cancer; and biopsychosocial unpleasantness of cancer
- Session 4 – psychology of supportive care; and therapeutic ingredients of psychological care
- Session 5 – clinical assessment of distress; and using the Distress Thermometer to make a psychosocial assessment
- Session 6 – psychological distress, stress and anxiety 2; and simple stress management techniques and approaches
- Session 7 – occupational factors in cancer care and staff health; and biopsychosocial factors within burnout and compassion fatigue
- Session 8 – review and application to local MDT setting; and building a model of supportive care within the finite resources of the MDT

The workshops are designed to be interactive, with small group activities and opportunities for questions. Participants are encouraged to discuss examples from their own clinical practice in order to ensure relevance and engagement. These workshops have been run for approximately three years, with the host trust now seeking to ensure

that they are effective in training staff in providing psychologically informed care, and to improve upon this where possible (in terms of both content and structure). There was therefore a high degree of service involvement in designing and conducting this improvement project, with senior members of oncology and haematology staff advising in the areas they believed it would be important to consider, and the ways in which they hoped the outcomes could be implemented.

Rationale and objectives

As described, there is a high prevalence of psychological distress in people diagnosed with cancer. This has been demonstrated to have significant effects upon cognitive and emotional functioning and quality of life, and may worsen over time if not treated appropriately. The importance of oncology staff having the necessary skills to screen and offer basic interventions for psychological distress has been outlined in the literature and recommended within national policy documents. Accordingly, this project comprised two phases, the first of which used semi-structured interviews to identify the psychological training and support needs of MDT members of staff working in the oncology departments of local hospitals. This information was used in conjunction with the Manual for Cancer Services: Psychological Support Measures (NCAT, 2011) to establish the nature and degree of input required from the clinical psychologist. In light of this, the second phase of the study used questionnaire measures to assess the extent to which the two day Level 2 Training Programme workshops run by the clinical psychologist meet the identified needs. The results of this project have then been used to provide recommendations for improving the Training Programme workshops, as well as to determine what other options there are for meeting the needs identified.

Phase 1 – What do MDT members of staff working in oncology units identify as being their psychological training and support needs?

Method

This service improvement project was granted full ethical approval by the University of Bath Psychology Departmental Ethics Board (ref: 12-162; Appendix C).

Design

For this phase of the study a qualitative semi-structured interview design was employed. This was chosen as it would allow participants to freely express their opinions regarding what their psychological training and support needs are, enabling this question to be answered as fully as possible.

Participants

The clinical psychologist identified 38 members of nursing and medical oncology staff who would be appropriate to interview (based on length of time in the service) to provide information on what the psychological training and support needs are for the staff group as a whole. From this group, a consecutive self-selecting sample of five members of staff was interviewed.

Materials

A semi-structured interview schedule, devised in collaboration with the clinical psychologist, was used in each of the interviews conducted (please see Appendix D). All interviews were audio recorded using a standard voice recorder.

Procedure

The clinical psychologist invited members of staff to participate in the interviews via email. Respondents were sent a copy of the study information sheet and interview dates and times were agreed upon. Participants were met with individually at the hospital and each provided signed informed consent before beginning. The semi-structured interview questions were then discussed, with each interview lasting approximately 30-45 minutes. The audio recordings of each interview were transcribed verbatim, and analysed using thematic analysis (Braun & Clarke, 2006), with overarching themes and subthemes being identified (with two additional raters confirming the identification of these themes). Recruitment for this phase of the study ended after no new themes emerged from the data (after five participants; cf. Guest, Bunce, and Johnson (2006)).

Results

The following four key themes were identified from the completed semi-structured interviews: ‘communication skills’ (including information giving, non-verbal communication, and listening), ‘recognising and dealing with emotions’, ‘offering

support and empathy' (including understanding what it's like to be a patient, providing holistic care throughout the journey, and delivering basic psychological interventions), and 'self-care' (including boundaries, reflection, peer support, and supervision). All four of these themes were present in all of the interviews conducted.

Communication skills

Each of the participants interviewed emphasised the important role they feel good communication skills play in reducing patients' levels of psychological distress, highlighting this as a primary training need for oncology staff. In particular, participants identified the importance of receiving training to provide "*really good, concise early information*" to patients, as this was identified as being "*really important*" (P1) in reducing levels of patient uncertainty. Participants also emphasised the importance of developing their listening and non-verbal communication skills in order to provide effective psychologically informed care to patients, as summarised by two participants as follows:

"listening, and attending, to people and what they're saying is one of the key things" (P2).

"90% of it is attitude... about how people speak to [patients]... how people smile... it's just about caring and showing that you care" (P5).

Recognising and dealing with emotions

Participants spoke of the importance of learning how to recognise a range of emotions (such as grief, shock, anxiety and anger) in their patients. The need to "*understand people's behaviour*", and how they may be "*behaving {in ways found challenging} because they're not coping*" (P5) was particularly emphasised. Some concerns were expressed that, without training, staff members may misunderstand a patient's behaviour and feel personally attacked, which may then lead them to show anger or defensiveness in return, as one participant commented:

"seeing it from the patient's perspective and understanding why they may be cross or angry, and how you don't react back to that behaviour" (P4).

Offering support and empathy

One topic about which participants spoke with particular enthusiasm was regarding staff members having some level of understanding of what it is like to be a patient with cancer. It was highlighted that this would allow staff to be better able to empathise with, and understand, their patients, as follows:

“putting yourself in their shoes, having some direct training that says ‘how do you think people feel?’” (P5).

Each of the participants also spoke of the importance of receiving training to provide holistic care to patients at different stages of their cancer journey, from diagnosis, through treatment, and onto discharge or end of life. Ending treatment and discharge appeared to be a particularly key time, with participants speaking most strongly about this aspect of the journey. One participant attributed this concern as resulting from the uncertainty that patients can feel at this time:

“all those feelings that happen when you finish – oh my God, am I cured? Is it coming back? You know, what do I do?” (P5).

Training in delivering basic psychological interventions, to patients and their family members, was also highlighted as being important. Participants expressed enthusiasm to learn simple and brief techniques such as breathing and relaxation exercises, as demonstrated by one participant who commented:

“I would like to [learn]... about the relaxation techniques... I think that would be a great thing to offer.” (P3).

Self-care

In addition to caring for their patients, participants also highlighted the importance of receiving training to help them care for themselves. In particular, awareness of boundaries, and *“understanding how far {staff} can go before they then need to hand over”* (P4) to the clinical psychologist, were identified as training needs. Concerns were expressed that, without training, some members of staff may try to take on too much work, or work outside of their competency level.

Reflecting upon the effects of the work was particularly highlighted as being important in enabling staff to best support their patients. This was expressed most strongly when discussing understanding one's own mortality:

“you have to have some idea about how you feel about your own mortality... staff can't help until they've worked out their own feelings” (P2).

Finally, providing peer support within teams, and receiving clinical supervision, were emphasised as being important aspects of delivering psychologically informed care. Participants highlighted these as being aspects which they valued, but concerns were widely expressed that they did not happen enough, as follows:

“I think you have to be able to support each other in a team” (P2).

“in an ideal world we'd all have, you know, regular supervision, and one to one sessions... and we need protected time to go as well” (P1).

Having identified the areas in which MDT members of oncology staff reported requiring training and support, phase 2 of this study went on to assess the extent to which these needs were currently being met, allowing for suggestions for improvements to be made where necessary.

Phase 2 – Does the Level 2 Training Programme workshop offered by the clinical psychologist meet the needs identified?

Method

Design

For this phase of the study a repeated measures questionnaire-based design was employed. This was chosen as it allowed for a direct assessment of the degree to which the workshops met the psychological training and support needs identified.

Participants

The clinical psychologist offers the Level 2 Training Programme workshop to MDT members of oncology staff from four hospitals within the same network. Members of staff attending the training between June 2013 and January 2014 were invited to

participate in the study. This sample comprised different members of staff from those invited to participate in the interview stage of this study. In total, 30 members of staff attended one of four workshops run over this period. All 30 completed the pre-training questionnaire, with 23 also completing the post-training questionnaire (representing a 77% response rate, which is considered adequate and acceptable (e.g. Nulty, 2008), meaning the data can be reliably interpreted from this sample).

Materials

A questionnaire was developed in order to assess whether the Level 2 Training Programme workshop is meeting the psychological training and support needs of the oncology staff. From the themes identified from the semi-structured interview data, 20 individual questionnaire items were derived (please see Appendix E). The questionnaire assesses each participant's perception of their knowledge and confidence regarding providing psychologically informed care to their patients (across an 11 point scale), and was designed to be administered pre and post-training. The only areas which had been identified as being important training needs which were not included in the questionnaire were those regarding supervision and peer support, as it was considered beyond the scope of the Level 2 Training Programme workshops to cover these areas.

The questionnaire appears to have good face validity as it covers the themes derived from the interviews and the areas stated in the Manual for Cancer Services: Psychological Support Measures (NCAT, 2011) as being important in Level 2 Training Programmes. In addition, a group of 15 local clinical psychologists working in physical health settings were asked at a 'Psychologists in Health' meeting to work in small groups to decide what elements they felt should be included in the Level 2 Training Programme workshops. The outcomes of these discussions were again in line with the questions included in the questionnaire, adding an element of content validity. It was beyond the scope of this study to assess the reliability of the questionnaire however (due primarily to service constraints and the small sample size participating in this study).

Procedure

At the beginning of the first day of the training workshop, participants were provided with a copy of the information sheet and asked to sign an informed consent form before completing the questionnaire. After having completed the workshop, participants were again asked to complete the questionnaire (these were completed either at the end of the

second day of training, or within a few weeks thereof). Post-training questionnaires were either handed in at the end of the training, or returned via email or post (both paper and electronic versions were provided to participants who did not return their questionnaires immediately following the training).

Results

Descriptive statistics

As shown in Table 1, the total mean score yielded by the questionnaire prior to the workshops was 121.3 (out of a possible 200), with the total post-training mean score having increased to 157.7. An increase in scores from pre to post-training was observed across all 20 questions, with mean pre-training scores ranging between 4 and 7.1 (out of a possible 10), and mean post-training scores ranging between 6.7 and 8.6.

Inferential statistics

The data were revealed to be non-parametric for the scores obtained on the individual questionnaire items, as a number of the Kolmogorov-Smirnov tests were significant, revealing that the data is not normally distributed. A Wilcoxon related-samples signed-rank test was conducted in order to compare the difference between total mean scores from pre to post-training, revealing a significant effect and large effect size; $W(22) = 276.00$, $z = 4.20$, $p < 0.001$, $d = -1.84$. This result suggests that participants' overall perceived knowledge and confidence regarding providing psychologically informed care to patients increased significantly as a result of completing the Level 2 Training workshop.

A series of Wilcoxon related-samples signed-rank tests were conducted in order to compare the differences between individual questionnaire item scores from pre to post-training. As Table 1 shows, significant differences and large effect sizes were revealed between the pre and post-training scores for each questionnaire item, suggesting that completing the Level 2 Training workshop led to a significant increase in participants' perceived knowledge and confidence regarding providing psychologically informed care to patients across every factor identified as being a training need (excluding supervision and peer support as previously discussed).

Table 1. Descriptive and inferential statistics of pre and post-workshop scores

Question topic	Pre-workshop mean (S.D.)	Post-workshop mean (S.D.)	W value	z value	Effect size (<i>d</i>)	<i>p</i> value
The nature of cancer-related distress	6.7 (1.3)	8.5 (1.0)	207.00	3.85	-1.55	<0.001
What it's like to be a cancer patient	5.4 (1.8)	7.4 (1.4)	248.50	4.00	-1.24	<0.001
Effects on the patient as a whole	6.6 (1.0)	8.2 (1.3)	168.00	3.64	-1.38	<0.001
Ending treatment (recovery)	6.2 (1.3)	7.8 (1.1)	136.00	3.55	-1.33	<0.001
Effects on the family	6.7 (1.5)	8.2 (1.0)	164.00	3.47	-1.18	0.001
Non-verbal communication	7.1 (1.1)	8.4 (1.0)	190.00	3.90	-1.24	<0.001
Referral to Levels 3 and 4	4.0 (2.2)	6.8 (2.5)	250.00	4.03	-1.19	<0.001
Information giving	7.0 (1.2)	8.3 (1.1)	200.00	3.61	-1.13	<0.001
Support around diagnosis	7.1 (1.5)	8.6 (0.9)	204.50	3.78	-1.21	<0.001
Working with distress	6.8 (1.5)	8.3 (1.0)	185.50	3.67	-1.18	<0.001
Empathy during treatment	7.1 (1.6)	8.4 (0.9)	157.50	3.17	-1.00	<0.005
Using relaxation techniques	4.3 (1.7)	6.7 (1.2)	251.00	4.09	-1.63	<0.001
Using the Distress Thermometer	4.4 (2.5)	7.8 (1.1)	231.00	4.03	-1.76	<0.001
Working with grief	5.5 (1.9)	7.5 (1.3)	187.00	3.73	-1.23	<0.001
Working with shock	5.8 (2.0)	7.4 (1.3)	216.00	3.54	-0.95	<0.001
Working with anxiety	6.1 (1.8)	7.7 (1.2)	185.50	3.69	-1.05	<0.001
Working with anger and aggression	5.7 (1.7)	7.6 (1.2)	184.00	3.61	-1.29	<0.001
Maintaining boundaries	6.7 (1.5)	8.2 (1.2)	190.00	3.88	-1.10	<0.001
Supporting end of life patients	5.7 (1.9)	7.6 (1.8)	184.00	3.61	-1.03	<0.001
Reflecting on work	6.2 (1.7)	8.2 (1.1)	231.00	4.05	-1.40	<0.001
Total score	121.3 (21.6)	157.7 (17.9)	276.00	4.20	-1.84	<0.001

Service Improvement: In what ways can the Training Programme workshops be improved to address any needs not being met, and what other provisions can be made available?

While participation in the Level 2 Training Programme workshops led to significant increases in participants' perceived knowledge and confidence with regards to the majority of factors identified from the semi-structured interviews as being training needs, recommendations can still be made, both for ways in which the benefits derived from the workshops themselves can be maximised, and for ways in which provisions other than the workshops can be made available.

Within Level 2 Training Programme workshops

The lowest mean post-training score was obtained for the question relating to participants' confidence using basic relaxation techniques (although there was still a large effect size and statistically significant increase in scores from pre to post-training). It is recommended therefore that time be allocated within the two day workshop to either allow participants to practice basic relaxation techniques in pairs, or for the facilitating clinical psychologist to lead a whole-group basic relaxation exercise to model appropriate style and content.

Other than perceived knowledge regarding onward referrals (please see below), the only other post-training mean scores to fall below 7.5 (i.e. three quarters along the rating scales) were for the questions regarding understanding of what it's like to be a cancer patient, and confidence regarding working with shock (although, again, there were still large effect sizes and statistically significant increases in scores from pre to post-training). It is recommended therefore that time be allocated within the two day workshop to invite participants to engage in an experiential exercise in which they imagine themselves undergoing an early stage of a cancer journey (such as imagining coming to the department, waiting to be seen, and being given a diagnosis, etc.).

In addition to Level 2 Training Programme workshops

Ratings of post-training perceived knowledge regarding onward referrals to the clinical psychologist varied according to whether or not participants worked at the same hospital as the clinical psychologist, with the mean score from those working in the

same hospital being 8.6, while the mean score from those working in different hospitals was 6.3. This difference in scores is likely to be a reflection of the fact that there is no clinical psychology provision in the hospitals in the network other than the one in which the clinical psychologist is based. It is recommended therefore that oncology service managers in the non-host hospitals establish a means of clinical psychology provision for those patients who require psychological input at Levels 3 and 4 of the Manual for Cancer Services: Psychological Support Measures (NCAT, 2011)'s model. It is suggested that this could best be achieved by increasing the number of clinical psychologists within the network, with time allocated to the different hospitals to be directed based on clinical need.

As discussed, it was not considered within the scope of the two day Level 2 Training Programme workshops to provide training related to supporting each other effectively within a team or to discuss ways of ensuring appropriate supervision for providing psychologically informed care to cancer patients. It is important to note however that the facilitating clinical psychologist does offer supervision groups for members of staff from the host hospital who have participated in the training. Through discussion with the clinical psychologist it became apparent however that attendance at the groups is approximately only 10%, leading to a recommendation being made to the oncology service managers that supervision time is protected, with staff members being encouraged to attend as far as possible. It is also recommended to the oncology service managers that a separate training workshop be offered to oncology staff members regarding effective team working and peer support.

Initial presentation to the service

The findings of this project were shared with the clinical psychologist who delivers the Level 2 Training Programme workshops. Emphasis was given to discussing how effective and well received the workshops tend to be, as well as discussions being held over ways in which the training could be improved to better meet the needs identified (see Service Improvement section above). The clinical psychologist responded in a positive manner to this feedback, reporting being pleased that the workshops are valued and effective. Inclusion of the exercises mentioned above (relaxation and imagining a part of a patient's journey) was discussed, with the clinical psychologist agreeing that these could be usefully implemented within the two day training workshops. It was also agreed that the service level recommendations regarding protecting time for clinical

supervision, offering training around effective peer support, and addressing the lack of onward referral options for other hospitals in the network should be discussed with oncology service managers. A provisional plan for feeding back this information to the service managers has been agreed. In addition, given the importance of offering effective screening and basic psychological interventions for people diagnosed with cancer, it has also been agreed that it would be useful for the outcomes and recommendations from this service improvement project to be shared with the local cancer network psychologists and the local 'Psychologists in Health' group. It is hoped that the recommendations from this project may then be adopted by other services delivering Level 2 Training Programme workshops also.

Discussion

This study was intended to identify the psychological training and support needs of MDT members of staff working in the oncology departments of local hospitals, and to offer suggestions for improvements to be made to the Level 2 Training Programme workshops run by the clinical psychologist in light of this. The importance of providing effective psychologically informed care to people diagnosed with cancer has been highlighted both within the research literature (e.g. Carlson & Bultz, 2003; Hack & Degner, 2004) and by national policy documents (e.g. DoH, 2007; NCAT, 2011). The results of this project indicate that, in order to provide effective psychologically informed care to oncology patients, staff identified their training needs as being primarily around communication skills, recognising and dealing with emotions, offering support and empathy, and self-care. The Level 2 Training Programme workshops offered by the clinical psychologist were found to be effective in increasing participants' levels of perceived knowledge and confidence across each of these domains. The findings of this study offer support therefore for the national implementation of Level 2 Psychological Care Training Programme workshops for MDT members of staff working with oncology patients, as specified in the Manual for Cancer Services: Psychological Support Measures (NCAT, 2011). Specifically, the results of this study suggest that time should be allocated within workshops to allow for training around communication skills, recognising and dealing with emotions, offering support and empathy, and self-care.

As described, the workshop-specific recommendations made have been accepted by the service which was seeking to improve its practice, and additional content will be included in light of this. Specifically, time will be allocated for engagement in a facilitator-led basic relaxation practice and an experiential exercise in which participants imagine themselves undergoing an early stage of a cancer journey. In addition, recommendations regarding supervision, peer support training and onward referral options will be taken forward to a service management level.

One limitation of this study is the small sample size available for the quantitative analysis. Further work, including a greater number of participants, may enable more in-depth analyses to be conducted which could look, for example, at whether different professional groups have different training needs and whether it would therefore be helpful for different aspects of the workshops to be emphasised depending upon the audience. Another potential limitation of this study is the inclusion of participants from different hospitals within the same network. This may have obscured site-specific needs or effects, as found for issues regarding referral to Levels 3 and 4 (for which closer analysis revealed staff members from the non-host hospital require further input whilst those from the host hospital do not).

It is important to note that this study was restricted to measuring changes in staff members' perceived knowledge and confidence levels. While these increased across every question measured in the pre and post-training questionnaires, any change in practice resulting from these increases cannot be established from this study. Objective measures of effectiveness in providing psychologically informed care to oncology patients would need to be completed both prior to, and following, training in order to address this question. There is also no indication from this study of whether the increases in perceived knowledge and confidence change over time. Re-administering the questionnaire after a suitable period of time (such as six months) would enable information regarding the longevity of the findings to be collected.

In conclusion, a sample of MDT members of oncology staff identified that, in terms of providing psychology informed care to their patients, their training needs were primarily around communication skills, recognising and dealing with emotions, offering support and empathy, and self-care. The Level 2 Training Programme workshops were found to be effective in increasing participants' levels of perceived knowledge and

confidence across each of these domains. Recommendations have been made for ways in which the workshops can be improved to better meet participants' needs (by the inclusion of two practical exercises), as well as additional structures which it would be beneficial for staff members to have in place (such as protected time for supervision).

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Investigating perceptions of disgust in older adult residential home
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This review is intended for submission to Emotion, and has been written and formatted accordingly (please see Appendix F). This journal has been chosen as it focuses on research regarding emotional processes, and accepts reports which investigate the relationships between emotions, health and psychopathology, with reports similar in nature to this one having therefore been published in this journal.

Abstract

As able-bodied people often become increasingly physically-dependent as they make the transition into older age, they may lose the ability to contain bodily fluids as they once had. Contact with bodily fluids is linked with feelings of disgust and, given the necessity of receiving assistance with intimate care activities, it has been suggested that self-focused disgust, and concerns over the disgust of others, may be important preoccupations in older people. This mixed-methods study therefore investigated feelings of disgust in fifty four physically-dependent older adults living in residential homes. Participants completed measures of disgust sensitivity, mood, and two new scales pertaining to feelings of self-disgust and perceived other-disgust when being assisted with intimate care activities. Results indicated that disgust was uncommon, although where present, self-disgust was related to perceptions of others' feelings of disgust and disgust sensitivity. These results were benchmarked against twenty one community-dwelling older adults, who reported believing they would feel significantly more disgusting if they were to start receiving assistance than those receiving assistance already did. Six of the residents who reported high levels of self-disgust also participated in semi-structured interviews. The thematic analysis was consistent with the quantitative results, with participants reporting that underlying protective factors, the use of strategies and carer characteristics reduced any feelings of disgust. The overall results are discussed with reference to the disgust literature, with recommendations being made for ways in which self-disgust can be minimised in residential homes.

Keywords: Disgust, Older adults, Residential home care

Introduction

Disgust is considered to be a universal emotion (Ekman, 1992) which may be triggered following, for example, exposure to bodily fluids. Most able-bodied people are able to contain their own bodily fluids, however as people become older, they may become increasingly infirm and be more likely to be exposed to situations which they and others may find disgusting (such as through incontinence for example). It may be suggested, therefore, that disgust focused on oneself, or the perceived disgust of others towards oneself, may be an important issue for physically-dependent older adults. In the present study therefore, disgust and associated psychological distress in this population is considered.

Disgust

Disgust is noted as having distinct behavioural, physiological, and expressive components (Rozin, Haidt, & McCauley, 2008) with it being suggested by authors, beginning with Darwin (1872), that these components are particularly strong as disgust plays an evolutionarily advantageous role (Curtis, Aunger, & Rabie, 2004). Rozin et al. (2008) outline a model of four stages of disgust, which have elaborated upon the innate oral rejection and distaste system. The first stage, 'core disgust', is elicited when a sense of potential oral incorporation, a sense of offensiveness, and a possibility of contamination are present. Offensive entities are typically characterised as being animals (including humans) and their waste products (Angyal, 1941; Martins & Pliner, 2006; Rozin & Fallon, 1987). The second stage, 'animal-nature disgust', is thought to involve entry into the body by routes other than (although not excluding) oral incorporation (Miller, 1986), and is triggered by stimuli which can be classified into one of the following four domains; inappropriate sexual acts, poor hygiene, death, or violations of the body 'envelope'. Rozin and Fallon (1987) argue therefore that anything that reminds human beings that they are 'animals', who will die, will lead to feelings of disgust. The third stage, 'interpersonal disgust', refers to feelings of aversion elicited by contact with others based on their strangeness, disease, misfortune, or moral taint (Rozin, Markwith, & McCauley, 1994). Finally, the fourth stage, 'moral disgust', refers to moral violations that do not involve the body, such as unfairness and injustice (Rozin, Haidt, & Fincher, 2009).

Self-disgust refers to the feelings of disgust outlined above being turned inwards on the self, and has been shown to correlate with general disgust sensitivity (Overton,

Markland, Taggart, Bagshaw, & Simpson, 2008). It has been argued that self-disgust is a distinct entity, although it shares some features with feelings of shame, guilt, anger, self-loathing, contempt and low self-esteem (Simpson, Hillman, Crawford, & Overton, 2010). Research has looked at the relationship between disgust, or self-disgust, and a range of psychopathologies (for a review please see Davey, 2011). In particular, self-disgust has been shown to partially mediate the relationship between dysfunctional cognitions and depression (Overton et al., 2008; Simpson et al., 2010), raising the possibility that stronger feelings of self-disgust are associated with higher levels of distress.

Disgust in older adults

Considering the breadth of research exploring feelings of disgust, there appears to be little research specifically addressing disgust processes in older adults (Sawchuk, 2009). There is evidence to suggest however, that, perhaps unlike other basic emotions, disgust sensitivity may be more durable over the lifespan (Calder et al., 2003; Davey, 1994 (although this finding is not always supported (eg. Curtis et al., 2004)), and may increase in the face of reminders about death (Bassett & Sonntag, 2010; Goldenberg et al., 2001). Such reminders may be experienced more frequently by older adults, as they are faced with the death of siblings, spouses, friends and others living within the same residential home. There is further evidence suggesting that older adults may view old age itself as being 'disgusting', and this appears to be more likely for individuals who give lower subjective ratings of their physical health status (Ron, 2007). For older adults with particularly poor physical health, the provision of assistance with intimate care activities by carers may be necessary, and the resulting contact with bodily excretions (such as urine, faeces, vomit and saliva) may also lead to feelings of disgust in carers (Jervis, 2001; van Dongen, 2001). The literature would suggest that care staff tend to 'adjust' to the potentially disgusting nature of their work, with time and the use of humour being instrumental in this process (Jervis, 2001). There does not, however, appear to be any literature addressing whether the disgust carers report sometimes feeling when working with older people has an effect on those older people's sense of self-disgust or mood in general.

Rationale

As described, given the high prevalence of physical care needs in older adult residential home populations, the presence of hypothesised feelings of self-disgust within this

population appears important to assess. While there is some research addressing the relationship between general disgust sensitivity and feelings of self-disgust, there does not appear to be any research examining the relationship of these factors with perceptions of others' feelings of disgust towards the individual. Investigating the extent to which these factors are inter-related will therefore be important because, where self-disgust is a problem, this may be in part a reflection of others' attitudes (such as the disgust felt by care staff). Further, investigating whether the previously established relationship between depression and self-disgust is replicated with an older adult sample may add further support for the independent role of disgust, over and above other mood problems.

Objectives and hypotheses

This project aimed to address the following objectives:

1. To investigate the extent to which physically-dependent older adults living in residential homes experience feelings of self-disgust. Given the high prevalence of physical care needs resulting in contact with bodily excretions, and the feelings of disgust reported by care staff, it is hypothesised that high levels of self-disgust will be reported.
2. To devise a measure to assess levels of self-disgust and perceived other-disgust within this population.
3. To investigate the relationship between feelings of self-disgust and perceived other-disgust. It is hypothesised that there will be a positive correlation between these factors.
4. To investigate the relationships between feelings of self-disgust and perceived other-disgust with disgust sensitivity, anxiety and depression. Given the findings reported by others, it is hypothesised that positive correlations will be found.
5. To investigate the extent to which a sample of community-dwelling, physically-able, older adults anticipate experiencing self-disgust if they were to become physically-dependent, relative to older adults already receiving assistance with intimate care activities. It is hypothesised that community-dwelling older adults will report anticipating feeling similarly high levels of self-disgust (again due to their expectation of having physical care needs resulting in contact with bodily excretions).

Method

This research project was granted full ethical approval by the University of Bath Psychology Departmental Ethics Board (ref: 13-116/14-006; Appendix G).

Design

A mixed methods design was employed for this study. A within group cross-sectional questionnaire design was used to investigate the relationships between feelings of self-disgust, perceived-other disgust, disgust sensitivity, depression and anxiety. A between groups causal-comparative questionnaire design was used to investigate the differences in questionnaire responses between people actually living in residential homes and the anticipated responses provided by those living in the community. The independent variable was the participants' accommodation-type, comprising two levels (residential home and community), with the dependent variables being the responses given across the questionnaires. Finally, a qualitative semi-structured interview design was used for the interview phase of the study, with the data being analysed using Thematic Analysis (Braun & Clarke, 2006).

Participants

Residential home sample: Fifty four older adults with physical disabilities requiring the provision of healthcare worker support for activities of daily living (such as eating, bathing, wound care and toileting) were recruited from seven residential homes in and around Bath. Length of time living in residential care ranged from one to 38 months, with an average duration of 14 months (S.D. = 12.56). Exclusion criteria included the presence of cognitive impairments of a severity such as to render the participant unable to provide informed consent or to be able to engage meaningfully in the study (assessed within informal discussions with residential home managers).

Interview sub-sample: From the residential home sample, six of the participants who obtained the highest scores on the disgust questionnaires, and who were available for interview, also participated in one-to-one semi-structured interviews. These participants were recruited from across four of the seven residential homes. Each participant had a number of intimate care needs (including needing help with bathing, dressing, toileting, wound care, and episodes of incontinence).

Community sample: Twenty one physically-able older adults living in the community in the same geographical area were also recruited to provide a benchmark for the questionnaire data.

Measures and materials

All participants completed the Disgust Scale – Revised (DS-R; Haidt, McCauley & Rozin, 1994, modified by Olatunji et al. 2007), the Generalised Anxiety Disorder Assessment (GAD-7; Spitzer, Kroenke, Williams & Lowe, 2006), and the Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer & Williams, 2001). Two novel measures were also developed to assess participants’ feelings of self-disgust, and their perceptions of others’ feelings of disgust.

The DS-R (Appendix H) is a 27 item self-report disgust sensitivity measure. Each question assesses either strength of agreement with a statement, or level of disgust in response to a particular experience, on a five point scale (from ‘strongly disagree’ to ‘strongly agree’ or ‘not disgusting at all’ to ‘extremely disgusting’ respectively), yielding a total score out of 100. This measure has been reported to have good psychometric properties and to be a valid and reliable index to establish disgust sensitivity (van Overveld, de Jong, Peters, & Schouten, 2011). It is important to note, however, that these psychometric evaluations are based on sample of young adults (mean age of 20 years) and the language used in the measure may be most appropriate and relevant to this group (please see ‘*Limitations*’ for further discussion on this point).

The GAD-7 (Appendix I) is a seven item self-report generalised anxiety scale. Each question applies to the past two weeks and assesses the frequency of anxiety symptoms on a four point scale (from ‘not at all’ to ‘nearly every day’). The suggested clinical cut off score is seven or above out of a possible 21. This measure has been reported to have good reliability, as well as criterion, construct, factorial, and procedural validity (Spitzer et al., 2006).

The PHQ-9 (Appendix J) is a nine item self-report depression scale. Each question applies to the past two weeks and assesses the frequency of depression symptoms on a four point scale (from ‘not at all’ to ‘nearly every day’). The suggested clinical cut off score is nine or above out of a possible 27. This measure has been reported to be a

reliable and valid measure of depression severity, and to have a strong utility in helping to inform diagnoses of depression (Kroenke et al., 2001).

The novel disgust measures (Appendix K) were designed for use together, with questions on one scale directly matching those on the other. Each measure consists of nine questions relating to care activities, applies to the past week, and assesses feelings of disgust on an 11 point scale (from 0, 'not at all disgusting / disgusted' to 10, 'completely disgusting / disgusted'). Given the potentially sensitive nature of the questions being asked, and to ensure the questions were worded in a clear and acceptable way, these measures were developed in collaboration with three older adults living in residential homes who themselves required physical assistance. They confirmed that the use of the word 'disgust' in these measures was appropriate and, in their opinions, not likely to cause offence or distress. Further input on the wording of the measures was also provided by a researcher with personal experience of Obsessive Compulsive Disorder (OCD) who further confirmed the acceptability of the term 'disgust' and advised on the most appropriate way of introducing the questionnaires to participants.

The novel disgust measures were adapted for use with the community sample of older adults. Each question was reworded to ask respondents how disgusting they imagined they would feel (and how disgusted they imagined staff members would feel) if they were to move into a residential home and require assistance with each of the activities.

A semi-structured interview schedule was used in each of the six interviews conducted (Appendix L). All interviews were audio recorded using a standard voice recorder.

Procedure

Residential home sample: Seven suitable local residential homes were identified, and recruitment was then conducted in collaboration with residential home managers. Every resident the managers indicated as being suitable and willing to be approached agreed to take part in the study. Following informed consent having been obtained, demographic information was gathered and all of the questionnaires were completed in the following order: DS-R, GAD-7, PHQ-9 and the novel self-disgust and perceived other-disgust questionnaires. Given the prevalence of visual difficulties within this population, each question was read aloud to participants and large-font response cards were given as a

reminder of the response scales for each questionnaire. In addition, 16 of the participants were also asked to complete the new self-disgust and perceived other-disgust measures a second time to allow reliability to be assessed. Retest data was obtained over the course of four to eight weeks following initial administration.

Interview sub-sample: Recruitment for the individual semi-structured interviews followed a similar procedure to that outlined above. These interviews focused upon what situations resulted in participants feeling disgusting, what factors affected the strength of these feelings and, where indicated, what had helped to reduce these feelings of disgust. Interviews lasted between 10 and 25 minutes, and were audio recorded to allow the verbatim transcription of the data. The transcripts were analysed using thematic analysis (Braun & Clarke, 2006), with two raters independently coding the data.

Community sample: Recruitment of older adults living within the community was conducted via contact with social groups and clubs. Participants were recruited from three separate sources (a bingo club, a community centre and a hospital volunteering group), with data gathering sessions then following the same format as was used with the participants living in residential homes.

Treatment of data

In the first part of the analysis, the new scales (measuring self-disgust and perceptions of others' feelings of disgust) were analysed in terms of their psychometric properties. The internal consistencies of the two scales were analysed for the community sample using Cronbach's alpha. It was not possible to determine the internal consistency for the residential home sample as too few participants answered enough questions (as the majority of the questions can be answered as 'Not Applicable'). Test-retest data were analysed for sixteen of the residential home participants using Spearman's rho, as Kolmogorov-Smirnov tests revealed that the data are not normally distributed.

The relationships between self-disgust, perceived other-disgust, general disgust sensitivity, depression and anxiety were then analysed using Spearman's rho. Power analyses revealed that it would be necessary to recruit 88 participants to allow for the detection of any correlations above $r = 0.3$ (medium effect size) (at a power of 0.9).

Finally, the scores obtained by the residential home participants on the DS-R, GAD-7, PHQ-9 and the new self-disgust and perceived other-disgust measures were compared to those obtained by the community sample using Mann-Whitney *U* tests. Power analyses revealed that it would be necessary to recruit a total of 140 participants (presuming equal group sizes) to allow for the detection of any differences above $d = 0.5$ (medium effect size) (at a power of 0.9).

Results

Demographic information

As Table 1 shows, the 54 residential home participants (76% female) had a mean age of 86 years (S.D. = 7.24, range = 62 to 96 years). Similarly, the six participants from this sample who participated in the interviews (five female) had a mean age of 85 years (S.D. = 7.08, range = 73 to 92 years), and the 16 participants from this sample who provided retest data (75% female) also had a mean age of 85 years (S.D. = 8.49, range = 62 to 94 years). The 21 community participants (71% female) had a mean age of 69 years (S.D. = 7.74, range = 60 to 88 years), which was significantly different from the residential home sample, $U(74) = 81$, $Z = -5.74$, $p = <0.0001$, $r = 0.66$.

The median score obtained by residential home residents on the GAD-7 was 2 (with 24% of participants scoring above the recommended clinical cut off), and on the PHQ-9 was 3.5 (with 19% scoring above the recommended clinical cut off). The community participants scored similarly on the GAD-7, obtaining a median score of 4 (with 48% scoring above the recommended clinical cut off), and on the PHQ-9, obtaining a median score of 2 (with 24% scoring above the recommended clinical cut off). Median scores on the DS-R were also similar for the residential home and community participants, at 51 and 46 respectively.

Table 1 also shows the ratings given on the self-disgust and perceived other-disgust measures, as well as the retest data for these scales. Overall, the ratings given by the residential home participants were very low for both the self-disgust and perceived other-disgust scales. Scores for the question related to feelings of self-disgust when incontinent, however, scored considerably higher (averaging 4.69) than the overall average. Both the residential home and community participants rated their self-disgust

(or expected self-disgust) as being greater than their perceived other-disgust, with the community sample providing higher scores for both.

Table 1. Descriptive statistics for scores obtained by each participant group on each measure.

	N	Age (S.D.)	Gender (% female)	DS-R* median total score (range)	GAD-7~ median total score (range)	PHQ-9† median total score (range)	Self-disgust scale median average score (range)	Other-disgust scale median average score (range)
Residential home participants	54	86 (7.24)	76	51 (14-91)	2 (0-18)	3.5 (0-19)	0.29 (0-4)	0 (0-7)
Retest sub- sample	16	85 (8.49)	75	52.5 (28-91)	3 (0-18)	3.5 (1-11)	0 (0-4)	0 (0-1.75)
Interview sub-sample	6	85 (7.08)	83	55.5 (18-91)	4 (0-11)	7 (0-10)	2.17 (0-4)	0.17 (0-2.5)
Community participants	21	69 (7.74)	75	46 (10- 100)	4 (0-21)	2 (0-15)	3.22 (0.33-7.56)	0.67 (0-6.56)

*Disgust Scale – Revised

~Generalised Anxiety Disorder Assessment

†Patient Health Questionnaire

Psychometric properties of the self-disgust and perceived other-disgust scales

Cronbach's alphas for the nine self-disgust and nine perceived other-disgust items were $\alpha = .84$ and $\alpha = .97$, respectively, indicating good internal consistency for the self-disgust scale and excellent internal consistency for the perceived other-disgust scale. Test-retest analyses, using Spearman's rho, revealed acceptable positive correlations both for scores on the self-disgust measure ($r = 0.76$, $p = 0.001$), and scores on the perceived other-disgust measure ($r = 0.61$, $p = 0.01$).

Relationship between self-disgust and perceived other-disgust

Spearman's rho analyses demonstrated that, for the residential home participants, there was a medium positive correlation between scores on the self-disgust and perceived other-disgust measure, with $r = 0.35$, $p = 0.009$. The relationship between the self-disgust and perceived other-disgust measure was not significant for the community sample however, with $r = 0.13$, $p = 0.57$. A Fisher r -to- z transformation revealed that these correlations were not significantly different, with $z = 0.86$, $p = 0.39$.

Zero-order correlations

When considering the relationship between the self-disgust measure and the DS-R, Spearman's rho analyses revealed significant relationships for the residential home participants, with $r = 0.51$, $p = <0.0001$, and the community participants, with $r = 0.79$, $p = <0.0001$. A Fisher r -to- z transformation revealed that these correlations were not significantly different, with $z = -1.86$, $p = 0.06$. When considering the relationship between the perceived other-disgust measure and the DS-R, Spearman's rho analyses revealed a significant relationship for residential home participants, with $r = 0.29$, $p = 0.03$, although the score for community participants did not reach statistical significance with $r = 0.29$, $p = 0.20$. No statistically significant relationships were found between self-disgust or perceived other-disgust and either the GAD-7 or PHQ-9 for either the residential home or community samples.

Comparison between residential home and community participants

Mann-Whitney U tests revealed that there was a significant difference between the scores selected on both the self-disgust and perceived other-disgust scales between the residential home and community participants (please see Table 1), with $U(74) = 1028$, $Z = 5.54$, $p = <0.0001$, $r = 0.64$ and $U(74) = 885$, $Z = 4.10$, $p = <0.0001$, $r = 0.47$, respectively. Differences on scores obtained for the DS-R, GAD-7 and PHQ-9 were not statistically significant between the groups.

Interview data

When discussing past experiences of self-disgust, overarching themes and subthemes were identified and inter-related as the thematic analysis suggested. Figure 1 shows this in terms of causes of self-disgust (including loss of functioning, embarrassment, self-consciousness and carer characteristics), alleviators of self-disgust (including change over time, strategies, protective factors and carer characteristics) and current feelings (including gratitude and acceptance). Each overarching theme was identified in the questionnaire transcripts of all six participants, with the number of participants for whom each subtheme was identified being detailed below. Ellipse heights & widths in Figure 1 are also scaled according to the number of participants reporting each subtheme.

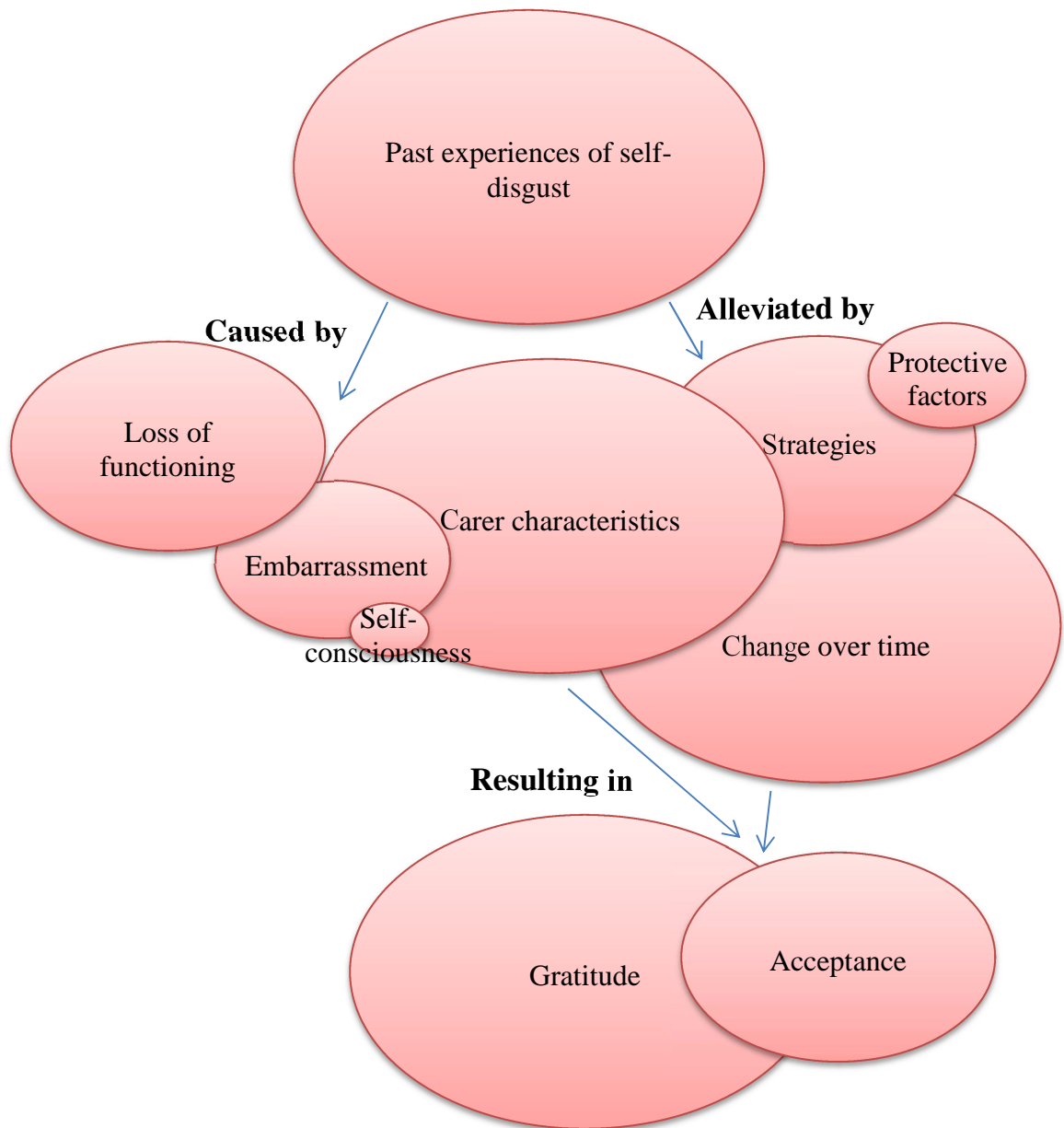


Figure 1. Themes identified from the semi-structured interviews.

Causes of self-disgust

When considering what had led to feelings of self-disgust, feelings of embarrassment were identified by three participants, with self-consciousness also being highlighted by one participant who commented: *“I get a bit embarrassed... I don’t like my body being exposed... you feel self-conscious”* (P1). Loss of functioning was also identified as being linked to feeling disgusting by four participants, as one participant explained, *“I wish I could do it myself... I never thought I’d come to this”* (P1).

Carer characteristics

All six of the participants interviewed discussed the influence of the carers' characteristics on their feelings of self-disgust. Important characteristics were identified as being the carer's age, gender and attitude. For instance, a number of the participants reported feeling more disgusting when being given assistance by younger care workers, as one participant highlighted, "*Well it's only because they're young... if I were young this is the last job I'd choose*" (P2). In addition, all but one of the female participants had received assistance from male carers, and they all identified feeling more disgusting when initially receiving assistance from a male carer, although this appears to have reduced over time, with one participant commenting:

"the first time I knew I was going to have a man, I was a bit apprehensive, but I needn't have been at all" (P2).

The attitude of the carers was highlighted by all of the participants as being important in minimising feelings of self-disgust, with kindness and respect being reported to be essential; "*everybody's so helpful and friendly... it's just their personality, and how they treat you*" (P6).

Alleviators of self-disgust

All six of the participants interviewed reported having initially experienced feelings of self-disgust when being given assistance with intimate care tasks, and all reported that these feelings had changed over time following repeated exposure to the situations. For instance, one participant summarised this change as follows: "*at first I didn't like it... But once you get used to it, it isn't so bad*" (P3), with another participant (P1) saying she had "*dreaded*" the first occasion on which she was assisted to have a bath, but no longer felt this way.

The use of strategies to minimise feelings of disgust were highlighted by all six of the participants interviewed. These strategies tended to involve the use of humour, open communication skills and practical strategies. For instance, one participant spoke about an occasion on which she had felt particularly disgusting when being assisted to have a bath, explaining that she had made a joke which "*broke the ice*", the result of which was that they "*had a laugh... and it made it better*" (P5). Another participant

highlighted the importance of talking openly to staff about how she was feeling when she had initially felt disgusting:

“talking about things, don’t let them ruffle you up, well it’s the best way to approach things” (P6).

The use of practical strategies to help alleviate feelings of disgust was also reported, with one participant describing the following approach: *“I spread the towel over me, I cover what I can, you know, bit by bit” (P1).*

Two participants also reported that having experienced certain situations in their pasts had led them to manage any feelings of disgust that arose. In particular, having been in a paid caring profession or having informally cared for a relative were identified as having been helpful, with two participants commenting:

“I think possibly things that I did before, and having served in the forces as well, you lose quite a number of your inhibitions. You have to. It conditions, you know” (P5).

“I’ve been a nurse all my working days you know and I’m quite used to it... I’ve been a carer all my life... You just get on with it” (P6).

Current feelings

All six of the participants interviewed reported feeling grateful for the care they received, and emphasised that this had replaced any feelings of disgust they had initially felt. Participants were often quick to begin the interviews by mentioning this, and returned often to this theme. For instance, when asked about the feelings of disgust she had identified in the questionnaires, one participant replied: *“I’m so grateful for them for doing it” (P1)*, before going on to describe the necessity of receiving care: *“Most people are grateful for to have it done, because where would we be?” (P1).*

Accepting the change in circumstances and the necessity of having assistance was also commented on by four of the participants as being a state which they felt they had achieved and which reflected them no longer experiencing feelings of self-disgust. One participant summarised this as follows:

“and so you learn to accept these, I think, well that’s how I feel, you know, I’ve learnt to accept these things” (P5).

Discussion

This study was intended to investigate feelings of self-disgust and perceived other-disgust in physically-dependent older adults living in residential homes. The results suggest that participants typically report not experiencing high levels of self-disgust when being assisted with intimate care activities. Further, they tend to report not believing that staff members feel disgusted when providing this assistance. The results also indicate that the new measures assessing feelings of self-disgust and perceived other-disgust appear to be psychometrically sound, although further analysis and replication is required to ensure this. Where feelings of self-disgust were revealed to be present, these were related to perceptions of others’ feelings of disgust towards the individual, and to general disgust sensitivity. There was a major discrepancy between how disgusting physically-able older adults living in the community indicated they would feel (and how disgusted they believed staff members would feel) if they were to start receiving assistance, and how those actually receiving assistance felt. It was reported by those receiving assistance, and who had scored highest on the self-disgust measure, that feelings of self-disgust had sometimes been experienced when they first began receiving care, but these feelings had decreased with exposure over time, being replaced by gratitude and acceptance. Important factors in this process appear to be the presence of underlying protective factors, the use of strategies and carer characteristics, which serve to reduce feelings of embarrassment, self-consciousness and loss.

The results obtained are inconsistent with the hypothesised suggestion that physically-dependent older adults living in residential homes would report experiencing feelings of self-disgust. Support was found, however, for the hypotheses that positive correlations would be found between feelings of self-disgust and perceptions of others’ feelings of disgust, as well as with general disgust sensitivity. The hypothesis that feelings of depression and anxiety would also correlate with self-disgust was not supported; although the study’s limited sample size has resulted in the power for these analyses being low. Finally, the hypothesis that community-dwelling older adults would report anticipating feeling similarly high levels of self-disgust as physically dependent older adults was partially supported, in that relatively high levels were reported but, given the

low scores reported by the residential home sample, the scores were significantly different between the two groups.

With reference to the Rozin et al. (2008) model of disgust, and given that the nature of the participants' physical care needs result in contact with bodily excretions, it may be surprising that feelings of self-disgust within this population were not found. The model would suggest that feelings of disgust would be elicited as stimuli proposed to trigger stage one, 'core disgust' and stage two, 'animal-nature disgust' are certainly present (with stage three, 'interpersonal disgust' and stage four, 'moral disgust' potentially being present in some situations). In line with this model, the participants interviewed did report having initially experienced feelings of self-disgust when first beginning to receive assistance with intimate care tasks. These feelings appear to have reduced quite rapidly however, with the results of this research offering support for the suggestions that feelings of disgust reduce with exposure (as discussed in the OCD and panic literatures, e.g. McKay (2006); Olatunji, Ciesielski, Wolitzky-Taylor, Wentworth, & Viar (2012); Olatunji, Huijding, de Jong, & Smits (2011)), with the use of cognitive reappraisals facilitating this process (e.g. Cisler, Olatunji, and Lohr, 2009). This process taking place in residential home residents appears to mirror the process identified as occurring within care staff who report adjusting over time (and with the use of strategies such as humour) to the potentially disgusting nature of their work (Jervis, 2001).

Implications of this study

In general, community-dwelling older adults reported believing that they would feel relatively high levels of self-disgust and perceived other-disgust if they were to move into a residential home and require assistance with intimate care activities. Residential home dwelling older adults receiving this assistance already, however, reported either not experiencing these feelings, or having overcoming any such feelings over time, and with the use of particular strategies (such as humour and open communication). It is recommended therefore that explicit information regarding this be included in introduction processes already in place for people moving into residential homes. It is suggested that attention be paid to reassuring people that these feelings usually reduce over time (if present at all), and that the importance of communicating openly with staff around these feelings be emphasised. It may also be useful to provide a list of strategies and tips suggested by other residents. In addition, given participants' reports that the attitude of staff members was influential in either causing or alleviating feelings of self-

disgust, it is recommended that attention be paid to this in staff training. Demonstrating kindness and gentleness appear to be particularly key in helping to reduce feelings of self-disgust and should, therefore, be emphasised.

The relationship found between the new self-disgust and perceived other-disgust questionnaires and the DS-R (Haidt, et al., 1994, modified by Olatunji et al. 2007) is encouraging. Although a useful measure for addressing general disgust sensitivity in community samples, the DS-R is too broad for assessing specific feelings of disgust when receiving assistance with intimate care activities. It is therefore suggested that the new measures are more suited to identifying feelings of self-disgust or perceived other-disgust in people who are physically dependent (although, as mentioned, further analysis is required to ensure the validity and reliability of these measures).

Given the finding that feelings of self-disgust were reportedly experienced by the interview participants when they began receiving care, further research investigating the prevalence of these feelings in other physically-dependent populations may be warranted. For instance, it would be interesting to investigate whether hospital patients requiring assistance with intimate care tasks report experiencing feelings of self-disgust, and whether these feelings are linked to low mood, and decrease over time, in the same manner as outlined in the current study. Research in this area could lead to further recommendations around hospital staff training and patient education.

Limitations of this study

This study is limited primarily in the fact that the majority of the analyses performed were correlational in nature, and by the use of cross-sectional comparisons, meaning that causality cannot be established. Longitudinal research, which follows people as they transition into care settings, and which assesses mood prior to beginning receiving care would help to clarify the direction of causality. Longitudinal research may also help clarify how long feelings of self-disgust remain a problem, allowing interventions to be targeted at an appropriate stage of an individual's transition into a residential home. It is also important to note that the new scales measure the intensity of feelings of disgust, not the degree to which these feelings are problematic. Further studies examining the clinical relevance of these feelings are therefore suggested.

In addition, as mentioned previously, the DS-R (Haidt, et al., 1994, modified by Olatunji et al. 2007) has been evaluated for use with groups of young adults, and the language used in the measure may not always be appropriate or relevant to older people (such as questions about sex education classes). The findings reported based upon this measure, therefore, must be interpreted with some degree of caution as, for a small number of questions, participants may have been providing responses for scenarios of which they have had no experience.

Finally, as reported, in order to explore possible feelings of self-disgust in more depth, six participants who had provided higher scores on the self-disgust measure were invited to participate in the semi-structured interviews. Given that, by definition, this group reported experiencing greater levels of self-disgust, it may be that the themes identified from their interviews cannot necessarily be generalised to those who initially reported experiencing lower (or no) levels of disgust. As such, it may be that these themes apply only to those individuals experiencing higher levels of self-disgust and not to physically-dependent older people in general. Further qualitative research exploring these issues with a greater number of participants (including those currently reporting feeling low levels of self-disgust) may be useful in addressing this.

In conclusion, feelings of self-disgust in physically-dependent older adults living in residential homes appear to be uncommon. Where present however, these are related to perceptions of others' feelings of disgust towards the individual and general disgust sensitivity. In addition, physically-able community-dwelling older adults reported that they would feel significantly more disgusting if they were to start receiving assistance than those actually receiving assistance did. Finally, residential home participants who experienced higher levels of self-disgust reported that underlying protective factors, the use of strategies and carer characteristics helped to reduce their feelings of disgust.

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Executive summary of report: Investigating perceptions of disgust in older
adult residential home residents

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Overview

This study was intended to investigate feelings of self-disgust, and perceptions of other people's disgust, in older adults living in residential homes who require assistance with intimate care activities (such as washing, dressing and toileting). New questionnaire measures were developed for this purpose. Relationships between these feelings of disgust and general disgust sensitivity, anxiety, and depression were also explored. Finally, differences between how disgusting people feel when receiving care, and how disgusting physically-able people think they would feel, were investigated. This summary will briefly outline the Introduction, Method, Results and Discussion (including recommendations) described in detail in the full report.

Introduction

As able-bodied people often become increasingly physically-dependent as they make the transition into older age, they may lose the ability to contain bodily fluids as they once had. Contact with bodily fluids is linked with feelings of disgust and, given the necessity of receiving assistance with intimate care activities, it has been suggested that self-focused disgust, and concerns over the disgust of others, may be an important preoccupation in older people. In addition, self-disgust has been shown to be related to general disgust sensitivity and depression, with stronger feelings of self-disgust being associated with higher levels of distress. Further, contact with bodily fluids has also been reported to lead to feelings of disgust in people caring for older adults.

Method

This study used questionnaires and interviews to investigate feelings of disgust in fifty four physically-dependent older adults living in residential homes. All participants completed measures of general disgust sensitivity, anxiety, depression, and two new scales asking about feelings of self-disgust and perceived other-disgust when being assisted with intimate care activities. Six of these residents (who gave higher scores for self-disgust) also participated in interviews about their experiences of feeling disgusting. In addition, twenty one physically-able older adults living in the community also completed the questionnaires, with the new scales being reworded to ask how

disgusting participants believed they would feel if they were to need assistance with intimate care activities.

Results

Results indicated that feelings of self-disgust and perceived other-disgust were uncommon in the residential home participants. Where feelings of self-disgust were present, self-disgust was related to perceptions of others' feelings of disgust towards the individual and general disgust sensitivity. There was also evidence suggesting that feelings of disgust had been strong when beginning to receive care, and were caused by embarrassment, self-consciousness and loss of functioning. These feelings were reported to have decreased over time, with the presence of underlying protective factors, the use of strategies (such as humour and open communication) and carer characteristics being important in this process. Any feelings of disgust were reported to have been replaced by feelings of acceptance and gratitude. Finally, the community-dwelling older adults reported that they would feel significantly more disgusting if they were to start receiving assistance than those actually receiving assistance did.

Discussion

The results obtained are inconsistent with the hypothesis that physically-dependent older adults living in residential homes would report experiencing feelings of self-disgust. Some participants did report having initially experienced feelings of self-disgust, with the results of this research offering support for suggestions that feelings of disgust reduce with exposure to the object considered disgusting. The results are consistent with the prediction that a relationship would be found between feelings of self-disgust and perceptions of others' feelings of disgust, and with previous research proposing that self-disgust is related to general disgust sensitivity. The new questionnaires have been shown to be useful in identifying feelings of self-disgust or perceived other-disgust in physically-dependent older people.

Recommendations

Given that community-dwelling older adults report believing that they would feel relatively high levels of self-disgust and perceived other-disgust if they were to move

into a residential home and require assistance with intimate care activities, it is recommended that explicit information regarding this be included in introduction processes already in place for people moving into residential homes. It is suggested that attention be paid to reassuring people that these feelings usually reduce over time (if present at all), and that the importance of communicating openly with staff around these feelings be emphasised. It may also be useful to provide a list of strategies and tips suggested by other residents. In addition, given participants' reports that the attitude of staff members was influential in either causing or alleviating feelings of self-disgust, it is recommended that attention be paid to this in staff training. Demonstrating kindness and gentleness appear to be particularly key in helping to reduce feelings of self-disgust and should, therefore, be emphasised.

Summary

In summary, feelings of self-disgust in physically-dependent older adults are uncommon, and are linked to perceptions of others' feelings of disgust towards the individual and general disgust sensitivity. Physically-able older adults may anticipate feeling high levels of self-disgust if they needed care, and feelings of self-disgust may be more common when some residents first begin receiving care, but these feelings typically decrease over time.

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Connecting Narrative

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Introduction

This connecting narrative will provide a reflective account of the processes involved in conducting the following pieces of research:

- Main Research Project (MRP): ‘Investigating perceptions of disgust in older adult residential home residents’;
- Service Improvement Project (SIP): ‘Profiling the psychological training and support needs of oncology staff, and evaluating the effectiveness of clinical psychology provision, in a general hospital department’;
- Critical Literature Review (CLR): ‘An evaluative review of the relationship between empathy and posttraumatic stress disorder’;
- Case Studies 1 to 5:
 - C1 – “‘I wish someone had told me before that I was allowed to be kind to myself’”. The importance of kindness and acceptance in CBT for OCD’;
 - C2 – ‘Opening locked doors: the use of CBT to facilitate acceptance of traumatic life events in recurrent depression and anxiety’;
 - C3 – “‘I just want them to think I’m good’”. Combining individual CBT with systemic CAT for depression and behaviour which challenges’;
 - C4 – “‘What would Commander Shepard do?’” Emphasising the use of metaphors within CBT for anxiety disorder with an adolescent’;
 - C5 – “‘Really paying attention makes so much difference!’” The integration of mindfulness within CBT for overcoming specific phobia within Crohn’s disease’.

The research process

Considering the entirety of the research component of the Doctorate in Clinical Psychology, being required to complete three separate pieces of research has given me the opportunity to gain a wide variety of skills and make contacts in different fields within the discipline. At times, the necessity of holding in mind three completely separate pieces of work, on top of clinical and academic work, has felt challenging, but I consider that this may well be valuable experience to prepare me for the realities of working as a qualified Clinical Psychologist in the NHS.

Overall, I found the development of the research questions to be one of the most challenging aspects of the entire research process. Before I began training, my usual practice had been to design research studies around clinical issues I had encountered, within a field in which I was already working and was already familiar. Being required to formulate research questions in different areas and without these arising from clinical work was difficult, and balancing my own interests and ideas with the areas of work considered appropriate by supervisors was also challenging. After some initial ideas being discarded, the general themes for my MRP and SIP were provided by field supervisors who advertised the research areas in which they were interested. As I am interested in working in clinical health, I chose project areas which would allow me to focus on different areas within this specialty (staff training within oncology for my SIP and feelings of self-disgust in physically-dependent older adults for my MRP). I then finalised the specific research questions and protocols for these two projects in collaboration with my field supervisors and university supervisors. In contrast, the research question for my CLR was developed independently of supervisor input (other than to approve the final idea). Similarly, I independently chose the clinical cases to write up as case studies on each of my clinical placements, with this feeling like a natural outworking of the work being undertaken, rather than feeling like ideas being developed in isolation.

While the initial ideas for my research projects were not based on work arising from clinical placements, it was interesting to see the way in which placement experiences helped to determine the direction the projects took, and to confirm the importance of conducting work in these areas. For instance, conversations I had with physically-dependent older adults on my older adult placement, and with physically-dependent people who were acutely unwell or injured on my health placement, highlighted the importance of looking at feelings of self-disgust within these populations. Similarly, working with people with cancer and with their healthcare professionals on my health placement reinforced the importance of providing effective psychological training to oncology staff; and working with people with PTSD on my adult and health placements confirmed the importance of looking at factors (such as empathy) which may be influential in the development or maintenance of this condition.

Recruitment of participants into both my MRP and SIP was hard work but relatively straightforward. My field supervisor was very helpful in facilitating recruitment into my

SIP (providing me with contact details and making introductions, for example). Given that my MRP field supervisor works in a different geographical area from the one in which I was planning to recruit, I was wholly responsible for making contacts and recruiting participants into this project. I was pleased that this was the case as it meant I did not have to spend time waiting for a busy clinician to have the time to do this, and I feel that having complete ownership of the recruitment process was useful in building relationships with the home managers.

Considering the three research studies, completing my CLR was certainly the most straightforward in terms of the work following the plans I had initially devised (although I was unsure of how exactly to complete a literature review and learnt a lot by undertaking this process). By contrast, the focus and methodologies for my SIP and MRP changed somewhat over the course of the process. For instance, with my SIP, balancing concerns around feasibility and fitting around the constraints of the service with gathering enough data in an effective and valid way led to the method of collecting qualitative data to change a few times between individual interviews and focus groups. This also provided a useful experience of learning to negotiate between different parties involved in the research project as my field supervisor and university supervisor had different views on what method would be the most suitable.

The project that changed the most from initial proposal to final write-up was my MRP. As I began collecting data for this project, it became apparent that feelings of self-disgust were not reported as being as great a problem as we had anticipated. While I was pleased to find that this was the case, it meant that intervening in this area (as we had planned) would not be necessary. Many of the participants I spoke with informed me that they had found feelings of self-disgust distressing in the past, when they first began receiving help with their intimate care activities, but that these feelings had decreased over time as they had become used to this. It appeared that any feelings of self-disgust or embarrassment had become replaced by feelings of acceptance and gratitude. Accordingly, in collaboration with my field and university supervisors, I decided to recruit an extra, physically-able, group of older adults into the project in order to see whether people's anticipated levels of self-disgust were greater than those we were actually finding in the residential home sample.

I was very grateful to have the assistance of university supervisors for analysing both the qualitative and quantitative data for my SIP and MRP, and am pleased that my skills in these areas have developed as a result of this. I found the processes of writing up my SIP and MRP to be fairly straightforward as they followed procedures I have used before. While it was very helpful to have university supervisor input into drafts, this at times had the potential to feel challenging where suggestions made were more about differences in style rather than content, and did not necessarily seem to be improvements or corrections.

Service user consultation

The only project for which I sought the input of people with personal experience was my MRP, for which I consider the input of physically-dependent older adults to have been incredibly valuable. I generally feel very passionate about involving people with personal experience in research planning and service development, and was disappointed that time restraints had meant that I was unable to do this in the initial stages of developing a research question. I had also felt a little concerned initially that the process of recruiting and meeting with people with personal experience may have proved to be time consuming for little benefit. This was certainly not the case however, as consulting with service users helped in the design of the two new questionnaires that were developed for my MRP and I found the feedback from these participants particularly reassuring in terms of my planned use of the word 'disgust', and asking people if they felt 'disgusting'. Obtaining this feedback turned out to be vital for the research, as many physically-able people to whom I spoke were concerned that the word would be offensive or distressing. Without having the assurance of people with lived experience that this term was appropriate, I would almost certainly have used a different, less suitable, term. The decision to use the word 'disgusting' was reinforced by the fact that the study participants themselves raised no concerns whatsoever and did not appear distressed at any point.

On reflection, and having spent a significant amount of time on my health placement working with people with cancer, I would have liked to have sought service user input for my SIP. It has been my experience that the people with cancer with whom I have worked have been well able to identify and communicate the psychologically-informed

techniques and behaviours that nursing staff use which they find particularly helpful, as well as behaviours and styles which are more likely to cause distress.

Ethical and R&D approval

I have been fortunate not to require NHS ethical approval for any of my research projects. The process of applying for University ethical approval for my SIP and MRP was straightforward and was useful in terms of clarifying my thinking. This was especially the case for finalising the details of how I was planning to implement data collection and analysis strategies. I completed my applications independently, but received helpful feedback and suggestions from my university supervisors. The only project for which I required R&D approval was my SIP. Applying for this proved to be slightly more difficult due to staffing issues within the R&D department in the NHS trust, which meant that this process took much longer than I had anticipated. While a little frustrating at times, this has provided a useful insight into the way in which conducting research in the NHS can sometimes be unpredictable.

Benefits of additional theoretical knowledge and experience

I feel that having previously worked with older adults in Assistant Psychologist and Research Assistant posts, and having conducted my undergraduate dissertation project with this client group, has contributed to both my enthusiasm, and my abilities, in working with this client group. In particular, I was aware of feeling more confident in terms of recruitment and engagement for my MRP than it is likely I would have otherwise. Previous knowledge of conducting research with this client group also meant that I was aware of the usefulness of adapting materials and questionnaire administration methods. Knowledge regarding the prevalence of sensory difficulties within this group meant that I developed in advance large font response cards for participants to select their answers, and that I was prepared to adapt the volume with which I spoke to participants as necessary.

Having developed a keen interest in Acceptance and Commitment Therapy (ACT) and mindfulness as an Assistant Psychologist, I have found I have drawn on some of these principles and techniques throughout many aspects of my clinical work. This is

reflected in many of my case studies, particularly C1, C4 and C5. In general, and throughout all of my case studies, I have enjoyed exploring ways in which a more traditional CBT approach can be adapted so that particular aspects are emphasised, or to allow the integration of other theoretically-consistent methods.

Outcomes of the research process

I feel that I have learnt a great deal from all of the research aspects engaged in during training. As mentioned, I did not have any experience of conducting evaluative literature reviews before starting training, and am pleased with the skills I have developed by undertaking this piece of work. In addition, both my MRP and SIP incorporated mixed-methods designs, enabling me to develop my skills in both quantitative and qualitative data collection and analysis. The vast majority of my research work prior to beginning training was quantitative in nature, and so I have particularly valued learning how to conduct qualitative research in a meaningful and rigorous way.

Consulting with service managers and senior staff for my SIP has been incredibly helpful in terms of making contacts and beginning to build relationships with people who could well be influential for my career progression (as this is one of the areas in which I would ideally like to specialise). In addition, I have been able to build on some of these relationships during my health placement and so am particularly pleased to have completed research in this area.

It is very important to me that the research I conduct is beneficial for clients (or for staff working with clients), and not simply being completed for its own sake. At times, reminding myself of the clinical utility of the research work I was undertaking was necessary, as I noticed on occasion feeling that I was working simply to fulfil course criteria, which considerably lessened my motivation and passion for engaging in the work. Having completed the research pieces however, I am pleased that reflecting on the entire research process and outcomes leaves me feeling that the work has been valuable aside from its contribution to my obtaining a doctorate.

Impact of learning on current practice

One of the most apparent ways in which I feel my learning from my research projects has affected my current practice has been the way in which I have approached certain aspects of my clinical health placement. While conducting my SIP, senior members of oncology staff repeatedly spoke to me of the importance of the attitude and body language staff members adopt when interacting with patients. While they spoke of relatively small and simple behaviours, our discussions, and the discussions I have since had with clients on my placement, have revealed that these are often overlooked. Having this knowledge has prompted me to remember to adopt as kind an attitude with clients as possible (down to even small behaviours like smiling and saying hello when walking past a patient's bed). In addition, having completed the CLR has, I believe, made some subtle differences to the way in which I read research articles. Throughout the course, critical thinking and analysis skills have been encouraged and this has been epitomised by undertaking the CLR.

The process of completing a case study on each placement has been very helpful in learning how to use this methodology. I believe that the scientific approach utilised in case studies is a useful and appropriate approach to take with all clinical work, and since the beginning of the course I have therefore used this approach as far as possible with all of my clients.

Feedback from others

Overall I have been very pleased with the responses participants have given regarding my SIP and MRP. In particular, I have been pleased with how positive the responses of residential home staff have been to being involved in my MRP, as they generally reported considering the project to be important and valuable. I found it particularly encouraging that, before meeting me, home staff would often say that there may be only a few residents with whom I could meet, but then, having met me, would be enthusiastic in facilitating my meeting with as many of the residents as possible. I consider this to be a reflection of how important they considered the research to be, and also of the implicit reassurance I was able to provide that a potentially sensitive topic would be approached with dignity and respect. Similarly, oncology staff members with whom I spoke about my SIP frequently expressed an opinion that the study was valuable and necessary. It

has also been my experience that the clients whose interventions I have written up as case studies have been very pleased to have been able to be involved in the creation of research and have been pleased to be asked for consent.

Future plans for involvement in research

The experiences I have had throughout many aspects of training have confirmed my decision to seek a career within Clinical Health Psychology. I therefore plan to continue working on research within this area as far as possible. As mentioned in my MRP, I would be interested in repeating this study with a population of people who are in acute hospitals, requiring assistance with intimate care activities because of injury or illness. This interest has stemmed from conversations I have had with a number of clients in the cancer unit on my placement, and I am particularly interested in investigating ways in which feelings of self-disgust can be minimised while people require assistance. I feel that this reflects my interest in conducting research that will directly benefit service users (as reflected in my CLR and MRP), although I am also interested in ways in which staff members working in acute hospitals can best be trained and supported, both for their benefit and for that of service users (as reflected in my choice of SIP). Given the often reported time constraints to conducting research as a qualified Clinical Psychologist however, the use of reporting clinical case studies appears to be one effective way of continuing to disseminate research. Having prepared a number of case reports to publishable standard during training, I feel I have developed a reporting style with which I am satisfied and could easily adapt for future reports.

Appendix A: Critical Literature Review: Instructions for Authors (Psychological Bulletin)

Psychological Bulletin® publishes evaluative and integrative research reviews and interpretations of issues in scientific psychology. Both qualitative (narrative) and quantitative (meta-analytic) reviews will be considered, depending on the nature of the database under consideration for review.

Integrative reviews or research syntheses focus on empirical studies and seek to summarize past research by drawing overall conclusions from many separate investigations that address related or identical hypotheses. A research synthesis typically presents the authors' assessments of

- the state of knowledge concerning the relations of interest;
- critical assessments of the strengths and weaknesses in past research; and
- important issues that research has left unresolved, thereby directing future research so it can yield a maximum amount of new information.

Both cumulative and historical approaches (i.e., ones that organize a research literature by highlighting temporally unfolding developments in a field) can be used. Integrative research reviews that develop connections between areas of research are particularly valuable.

Manuscripts dealing with topics at the interface of psychological sciences and society are welcome, as are evaluations of applied psychological therapies, programs, and interventions. Expository articles may be published if they are deemed accurate, broad, clear, and pertinent.

Methodological articles that previously were submitted to *Psychological Bulletin* should now be submitted to *Psychological Methods*. Original theoretical articles should be submitted to *Psychological Review*, even when they include summaries of research. Research syntheses should be submitted to *Psychological Bulletin* even when they develop integrated theoretical statements.

Submission

Submit manuscripts electronically through the Manuscript Submission Portal.



All efforts should be undertaken to submit manuscripts electronically to the editor. Files can be sent in Microsoft Word, or as a PDF file. The version sent should be consistent with the complete APA-style printed version.

Dolores Albarracín, Incoming Editor

University of Pennsylvania

3620 Walnut Street, Office 346

Philadelphia, PA 19104

General correspondence may be directed to the [Editor's Office](#).

In addition to addresses and phone numbers, please supply electronic mail addresses and fax numbers, if available, for potential use by the Editorial Office and later by the Production Office.

Keep a copy of the manuscript to guard against loss.

Masked Review Policy

The identities of authors will be withheld from reviewers and will be revealed after determining the final disposition of the manuscript only upon request and with the permission of the authors.

Authors are responsible for the preparation of manuscripts to permit masked review.

Manuscripts submitted electronically should include all author names and affiliations, as well as the corresponding author's and co-authors' contact information, in the box labeled "cover letter," not in the manuscript file.

Every effort should be made to ensure that the manuscript itself contains no clues to the authors' identities, including deletion of easily identified self-references from the reference list.

If an author feels that revealing his or her identity is critical to receiving a fair review, such a request along with its justification should be made in the cover letter accompanying the manuscript.

Please ensure that the final version for production includes a byline and full author note for typesetting.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's [Checklist for Manuscript Submission](#) before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:

- Go to the Text section of the Insert tab and select Object.
- Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

We request that runnable source code be included as supplemental material to the article. For more information, visit [Supplementing Your Article With Online Material](#).

In the Text of the Article

If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font with a type size of 8 points. We will make an image of each segment of code in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.) If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Submitting Supplemental Materials

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see [Supplementing Your Article With Online Material](#) for more details.

Abstract and Keywords

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

- **Journal Article:**

Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin*, 139, 133–151. <http://dx.doi.org/10.1037/a0028566>

- **Authored Book:**

Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

- **Chapter in an Edited Book:**

Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, [please see the general guidelines](#).

When possible, please place symbol legends below the figure instead of to the side.

Original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay

- \$255 for one figure
- \$425 for two figures
- \$575 for three figures
- \$675 for four figures
- \$55 for each additional figure

Permissions

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- For manuscripts **not** funded by the Wellcome Trust or the Research Councils UK

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Ethical Principles

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.

Authors are required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment.

- [Download Certification of Compliance With APA Ethical Principles Form \(PDF, 26KB\)](#)

The APA Ethics Office provides the full [Ethical Principles of Psychologists and Code of Conduct](#) electronically on its website in HTML, PDF, and Word format. You may also request a copy by [emailing](#) or calling the APA Ethics Office (202-336-5930). You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611.

Appendix B: Service Improvement Project: Instructions for Authors (Journal of Psychosocial Oncology)

Aims and Scope: *RNdex Top 100 by Silverplatter*

Here is your single source of international integrated information on providing the best oncology psychosocial care possible from the many disciplines involved in care and research of those influenced by cancer. The *Journal of Psychosocial Oncology* is an essential source for up-to-date clinical and research material geared toward health professionals who provide psychosocial services to cancer patients, their families, and their caregivers. The journal—the first interdisciplinary resource of its kind—is in its fourth decade of examining the influence of a cancer diagnosis on the patient, their families, and their caregivers, hypothesis testing, the effectiveness of interventions, the application of theory, and program evaluation research on critical areas of cancer care. Implications for future research and clinical practice based on the findings presented are encouraged.

The journal's editorial board represents many different fields in psychosocial oncology, including education, epidemiology, health advocacy, medical oncology, neurology, nursing, nutrition, pastoral counseling, physical therapy, psychiatry, psychology, public health, social work, sociology, and surgical oncology. The *Journal of Psychosocial Oncology* includes original experimental and observational research studies, quantitative and qualitative studies, evaluation studies, and clinical and case studies. The journal also publishes critical reviews that build on existing knowledge.

Address manuscripts to the Editor:

Journal of Psychosocial Oncology receives all manuscript submissions electronically via their ScholarOne Manuscripts website located at:

<http://mc.manuscriptcentral.com/WJPO>. ScholarOne Manuscripts allows for rapid submission of original and revised manuscripts, as well as facilitating the review process and internal communication between authors, editors and reviewers via a web-based platform. For ScholarOne Manuscripts technical support, you may contact them by e-mail or phone support via <http://scholarone.com/services/support/>. If you have any other requests please contact the journal at mailforkrish@gmail.com. Send your editorial inquiries directly to the Editor, Dr. Zabora (James.Zabora@inova.org) or to the Managing Editor, Dr. S. Singh (mailforkrish@gmail.com). Authors must complete a

Copyright Transfer Form Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. As an author, you are required to secure permission if you want to reproduce any figure, table, or extract from the text of another source. This applies to direct reproduction as well as “derivative reproduction” (where you have created a new figure or table which derives substantially from a copyrighted source). All accepted manuscripts, artwork, and photographs become the property of the publisher. All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text in the abstract.

References:

References, citations, and general style of manuscripts should be prepared in accordance with the APA Publication Manual, 6th ed. Cite in the text by author and date (Smith, 1983) and include an alphabetical list at the end of the article.

Examples:

Journal:

Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. *Archives of Sexual Behavior*, 7(6), 417-427.

Book:

Millman, M. (1980). *Such a pretty face*. New York, NY: W.W. Norton.

Contribution to a Book:

Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), *Ageing in the 1980s* (pp. 239–252). Washington, DC: American Psychological Association.

Illustrations:

Illustrations submitted (line drawing, halftones, photos, photomicrographs, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines:

300 dpi or higher

Sized to fit on journal page

EPS, TIFF, or PSD format only

Submitted as separate files, not embedded in text files

Color Reproduction:

Color art will be reproduced in color in the online publication at no additional cost to the author. Color illustrations will also be considered for print publication; however, the author will be required to bear the full cost involved in color art reproduction. Please note that color reprints can only be ordered if print reproduction costs are paid. Print Rates: \$900 for the first page of color; \$450 per page for the next three pages of color. A custom quote will be provided for articles with more than four pages of color. Art not supplied at a minimum of 300 dpi will not be considered for print.

Tables and Figures:

Tables and figures (illustrations) should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet.

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Page proofs are sent to the designated author using Taylor & Francis' Central Article Tracking System (CATS). They must be carefully checked and returned within 48 hours of receipt.

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Appendix C: Service Improvement Project: Ethical approval

Date: 22/01/2013 11:41:25 BST
From: Helen Lucey <hl259@bath.ac.uk>
To: Amanda Laffan <ps3ajs@bath.ac.uk>
Subject: Re: Ethics 12-162

Dear Amanda

Thank you for attending to those last queries. I can now confirm that you have full ethical approval for your study (Reference Number 12-162).

Best wishes with your research.
Helen Lucey
Chair Psychology Ethics Committee

Date: 09/04/2013 13:35:05 BST
From: Helen Lucey <H.Lucey@bath.ac.uk>
To: Amanda Laffan <ps3ajs@bath.ac.uk>
Subject: Re: Ethics 12-162

Dear Amanda

The following amendments to the existing study 'Investigating the psychological training needs of oncology staff, and evaluating the effectiveness of psychology provision' (Reference Number 12-162) have been approved:

1. Replacing focus groups with one-to-one interviews with staff members.
- You have full approval to continue with your study.

Best wishes with your research.
Helen Lucey
Chair of Psychology Ethics Committee

Date: 14/10/2013 13:32:59 BST
From: ps3ajs@bath.ac.uk
To: Helen Lucey <H.Lucey@bath.ac.uk>
Subject: Re: Ethics 12-162

Dear Helen,

I am emailing to inform you of some changes we are considering making to this project, and to find out if I need to re-apply for ethical approval etc. The study is looking at the effectiveness of some staff training carried out at the RUH in Bath, and we had initially thought this would involve only RUH staff (and this is what we have approval for). However, the training will now be offered to staff from other hospitals (still taking place at the RUH, with an RUH trainer) and we would like to include these participants in the data collection. Do we need to amend the ethics application?

Best wishes, Amanda
Amanda Laffan
Clinical Psychologist in Training
University of Bath

Date: 24/10/2013 15:37:12 BST
From: Psychology-Ethics <psychology-ethics@bath.ac.uk>
To: ps3ajs@bath.ac.uk
Subject: Re: Ethics 12-162

Dear Amanda

Reference Number 12-162

Thank you for submitting a request for minor amendment to the above study. I can confirm that this amendment is approved and you are able to recruit participants as indicated in your amended documentation.

Best wishes with your research.
Acting Chair Psychology Ethics Committee

Appendix D: Service Improvement Project: Semi-structured interview schedule

- a. What do you think the psychological needs of the cancer patients here are?
- b. How can these needs best be met by healthcare professionals (other than psychologists)?
- c. Are there any psychological interventions that you would like healthcare staff to be able to use?
- d. Are there any psychological concerns that commonly arise?
- e. What are the most challenging situations?
- f. What unmet needs arise within your patient group?
- g. How could staff be best trained to provide supportive care to their patients?
- h. How could staff be best supported to provide supportive care to their patients?
- i. In an ideal world, what additional things would you wish to see implemented within the service?
- j. Is there anything else relevant that we have not discussed?

Name:_____ Job title:_____

(Please note: questionnaires will **not** be read by any members of staff at the RUH)

- Please read the following questions carefully and for each one give a number based on the scales shown:

0	1	2	3	4	5	6	7	8	9	10
Not at all									Completely	
sufficient									sufficient	

1. How sufficient do you feel your knowledge is about the nature of distress related to cancer?	
2. How sufficient do you feel your knowledge is of what it's like to be a cancer patient?	
3. How sufficient do you feel your knowledge is of the way in which cancer and treatment affects a person as a whole (e.g. side effects)?	
4. How sufficient do you feel your knowledge is about the issues that can arise when patients end treatment (i.e. in recovery)?	
5. How sufficient do you feel your knowledge is of the effects of cancer on a patient's family?	
6. How sufficient do you feel your knowledge is about non-verbal communication with patients (e.g. body language and facial expression)?	
7. How sufficient do you feel your knowledge is about the referral process to level 3 or 4 for psychological input?	

0 1 2 3 4 5 6 7 8 9 10
 No confidence Complete
 at all confidence

8. How confident do you feel giving information in a way that patients understand?	
9. How confident do you feel supporting a patient who has just received a diagnosis?	
10. How confident do you feel communicating effectively with a very distressed patient?	
11. How confident do you feel demonstrating empathy with patients going through treatment?	
12. How confident do you feel using basic relaxation techniques with patients?	
13. How confident do you feel using the 'Distress Thermometer' with patients?	
14. How confident do you feel working with grief?	
15. How confident do you feel working with shock?	
16. How confident do you feel working with anxiety?	
17. How confident do you feel working with anger and aggression?	
18. How confident do you feel maintaining boundaries within your work with patients?	
19. How confident do you feel emotionally supporting end of life patients?	
20. How confident do you feel reflecting on the emotional nature of your work?	

Appendix F: Main Research Project: Instructions for Authors (Emotion)

Emotion[®] publishes significant contributions to the study of emotion from a wide range of theoretical traditions and research domains. The journal includes articles that advance knowledge and theory about all aspects of emotional processes, including reports of substantial empirical studies, scholarly reviews, and major theoretical articles.

Submissions from all domains of emotion research are encouraged, including studies focusing on cultural, social, temperament and personality, cognitive, developmental, health, or biological variables that affect or are affected by emotional functioning. Both laboratory and field studies are appropriate for the journal, as are neuroimaging studies of emotional processes. Studies of psychopathology contributing to the understanding of the role of emotional processes in affective and behavioral disorders are also welcome. Reports of work at the animal and molecular levels will be considered if they help to elucidate fundamental mechanisms of emotion.

Most of the articles published in *Emotion* will be reports of original research, but other types of articles are acceptable.

- Case studies from either a clinical setting or a laboratory will be considered if they raise or illustrate important questions that go beyond the single case and have heuristic value.
- Articles that present or discuss theoretical formulations of emotion and related affective phenomena, or that evaluate competing theoretical perspectives on the basis of published data, may also be accepted.
- Comprehensive reviews of the empirical literature in an area of study are acceptable if they contain a meta-analysis and/or present novel theoretical or methodological perspectives.
- Comments on articles published in the journal will be considered.

Submission

Submit manuscripts electronically through the [Manuscript Submission Portal](#) in Word Document format (.doc).



All tables and figures should be included in the manuscript file.

David DeSteno

Northeastern University

Boston, MA 02115

General correspondence may be directed to the [Editor's Office](#).

Masked Review Policy

Masked reviews are optional, and authors who wish masked reviews must specifically request them when they submit their manuscripts.

For masked reviews, the manuscript must include a separate title page with the authors' names and affiliations, and these ought not to appear anywhere else in the manuscript.

Footnotes that identify the authors must be typed on a separate page. Authors are to make every effort to see that the manuscript itself contains no clues to their identities.

If your manuscript was mask reviewed, please ensure that the final version for production includes a byline and full author note for typesetting.

Manuscript Submission Guidelines

In addition to addresses and phone numbers, authors should supply email addresses and fax numbers for use by the editorial office and later by the production office. The majority of correspondence between the editorial office and authors is handled by email, so a valid email address is important to the timely flow of communication during the editorial process.

Authors should provide email addresses in their cover letters and should keep a copy of the manuscript to guard against loss. Manuscripts are not returned.

Manuscripts for *Emotion*[®] can vary in length; typically they will range from 10 to 40 double-spaced manuscript pages. Manuscripts should be of sufficient length to ensure theoretical and methodological competence.

Most of the articles published in *Emotion* will be reports of original research, but other types of articles are acceptable.

- Case studies from either a clinical setting or a laboratory will be considered if they raise or illustrate important questions that go beyond the single case and have heuristic value.
- Articles that present or discuss theoretical formulations of emotion and related affective phenomena that evaluate competing theoretical perspectives, or that

offer innovative commentary or analysis on timely topics of inquiry may also be accepted.

- Comprehensive reviews of the empirical literature in an area of study are acceptable if they contain a meta-analysis and/or present novel theoretical or methodological perspectives.
- Comments on articles published in the journal will be considered.

To facilitate a more complete understanding of the reported results, submissions based on empirical findings must report effect sizes and 95% confidence intervals for the primary findings in each study.

Brief Reports

Emotion also publishes brief reports. Manuscripts submitted as Brief Reports should not exceed 2,500 words, exclusive of references and figure captions. There should be no more than 2 figures or tables and no more than 30 references.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's [Checklist for Manuscript Submission](#) before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Below are additional instructions regarding the preparation of display equations, computer code, and tables.

Display Equations

We strongly encourage you to use MathType (third-party software) or Equation Editor 3.0 (built into pre-2007 versions of Word) to construct your equations, rather than the equation support that is built into Word 2007 and Word 2010. Equations composed with the built-in Word 2007/Word 2010 equation support are converted to low-resolution graphics when they enter the production process and must be rekeyed by the typesetter, which may introduce errors.

To construct your equations with MathType or Equation Editor 3.0:

- Go to the Text section of the Insert tab and select Object.

- Select MathType or Equation Editor 3.0 in the drop-down menu.

If you have an equation that has already been produced using Microsoft Word 2007 or 2010 and you have access to the full version of MathType 6.5 or later, you can convert this equation to MathType by clicking on MathType Insert Equation. Copy the equation from Microsoft Word and paste it into the MathType box. Verify that your equation is correct, click File, and then click Update. Your equation has now been inserted into your Word file as a MathType Equation.

Use Equation Editor 3.0 or MathType only for equations or for formulas that cannot be produced as Word text using the Times or Symbol font.

Computer Code

Because altering computer code in any way (e.g., indents, line spacing, line breaks, page breaks) during the typesetting process could alter its meaning, we treat computer code differently from the rest of your article in our production process. To that end, we request separate files for computer code.

In Online Supplemental Material

We request that runnable source code be included as supplemental material to the article. For more information, visit [Supplementing Your Article With Online Material](#).

In the Text of the Article

If you would like to include code in the text of your published manuscript, please submit a separate file with your code exactly as you want it to appear, using Courier New font with a type size of 8 points. We will make an image of each segment of code in your article that exceeds 40 characters in length. (Shorter snippets of code that appear in text will be typeset in Courier New and run in with the rest of the text.) If an appendix contains a mix of code and explanatory text, please submit a file that contains the entire appendix, with the code keyed in 8-point Courier New.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Submitting Supplemental Materials

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see [Supplementing Your Article With Online Material](#) for more details.

Abstract and Keywords

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

- **Journal Article:**

Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin*, 139, 133–151. <http://dx.doi.org/10.1037/a0028566>

- **Authored Book:**

Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

- **Chapter in an Edited Book:**

Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, [please see the general guidelines](#).

When possible, please place symbol legends below the figure instead of to the side.

APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

For authors who prefer their figures to be published in color both in print and online, original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay:

- \$900 for one figure
- An additional \$600 for the second figure
- An additional \$450 for each subsequent figure

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In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.

Authors are required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment.

- [Download Certification of Compliance With APA Ethical Principles Form \(PDF, 26KB\)](#)

The APA Ethics Office provides the full [Ethical Principles of Psychologists and Code of Conduct](#) electronically on its website in HTML, PDF, and Word format. You may also request a copy by [emailing](#) or calling the APA Ethics Office (202-336-5930). You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611.

Appendix G: Main Research Project: Ethical approval

Date: 03/07/2013 14:42:31 BST
From: Jeffrey Gavin <J.Gavin@bath.ac.uk>
To: Amanda Laffan <A.J.Laffan@bath.ac.uk>,
Subject: ethics - ref 13-116

Dear Amanda Laffan

Reference Number 13-116

The ethics committee have considered your ethics proposal for the study entitled 'Investigating Perceptions of Disgust in older adult residential home residents' and have given it full ethical approval.

Best wishes with your research.

Dr Jeff Gavin

Acting Chair of Psychology Ethics Committee

Date: 10/02/2014 10:48:38 BST
From: Psychology Ethics Committee <psychology-ethics@bath.ac.uk>
To: Amanda Laffan <A.J.Laffan@bath.ac.uk>
Subject: Ethics 14-006

Dear Amanda Laffan

Reference Number 14-006

The ethics committee have considered your ethics proposal for the study entitled 'Investigating perceptions of disgust in older adult residential home residents - intervention phase' and have given it full ethical approval.

Best wishes with your research.

Dr Helen Lucey

Chair Psychology Ethics Committee

University of Bath

Date: 25/02/2014 09:49:50 BST
From: ps3ajs@bath.ac.uk
To: Psychology Ethics Committee <psychology-ethics@bath.ac.uk>
Subject: Re: Ethics 14-006

Dear Dr Lucey,

Thank you for your email confirming that full ethical approval has been granted for the study entitled 'Investigating perceptions of disgust in older adult residential home residents - intervention phase' (Reference Number 14-006). I am emailing to let you know about an amendment we would like to make to the study.

For this phase of the study, I was aiming to complete 2 interviews and brief interventions around participants' feelings of self-disgust. Having completed the interviews however, we now think that there is no need to offer an intervention around this. I would like to conduct an extra 4 interviews (so a total of 6) to make sure this is the case. I would also like to recruit a sample of 20 community-dwelling older adults who do not need assistance with care activities in order to benchmark a couple of the disgust questionnaires I administered in phase 1 of the study (Reference Number 13-116). These questionnaires will be slightly reworded, and will ask participants to imagine how they think they would feel if they were to receive assistance with care activities. (I will also ask these participants to complete the brief depression and anxiety measures the residential home participants completed - PHQ 9 and GAD 7).

I am attaching an information sheet, consent form and the reworded questionnaires for the community sample. Please let me know if you need any further information.

Best wishes, Amanda
Amanda Laffan
Clinical Psychologist in Training
University of Bath

Date: 05/03/2014 15:27:36 BST
From: Psychology Ethics Committee <psychology-ethics@bath.ac.uk>
To: ps3ajs@bath.ac.uk
Subject: Re: Ethics 14-006

Dear Amanda

Thank you for informing me of those proposed amendments to the existing study (Reference Number 14-006). I can confirm that you have full ethical approval to make those changes and continue with your research.

Best wishes
Dr Helen Lucey
Chair Psychology Ethics Committee
University of Bath

Appendix H: Main Research Project: Disgust Scale – Revised (DS-R)

Name:

Date:

Please indicate how much you agree with each of the following statements, or how true it is about you. Please write a number (0-4) to indicate your answer:

0 = Strongly disagree (very untrue about me)

1 = Mildly disagree (somewhat untrue about me)

2 = Neither agree nor disagree

3 = Mildly agree (somewhat true about me)

4 = Strongly agree (very true about me)

- ____ 1. I might be willing to try eating monkey meat, under some circumstances.
- ____ 2. It would bother me to be in a science class, and to see a human hand preserved in a jar.
- ____ 3. It bothers me to hear someone clear a throat full of mucous.
- ____ 4. I never let any part of my body touch the toilet seat in public restrooms.
- ____ 5. I would go out of my way to avoid walking through a graveyard.
- ____ 6. Seeing a cockroach in someone else's house doesn't bother me.
- ____ 7. It would bother me tremendously to touch a dead body.
- ____ 8. If I see someone vomit, it makes me sick to my stomach.
- ____ 9. I probably would not go to my favorite restaurant if I found out that the cook had a cold.
- ____ 10. It would not upset me at all to watch a person with a glass eye take the eye out of the socket.
- ____ 11. It would bother me to see a rat run across my path in a park.
- ____ 12. I would rather eat a piece of fruit than a piece of paper
- ____ 13. Even if I was hungry, I would not drink a bowl of my favorite soup if it had been stirred by a used but thoroughly washed flyswatter.
- ____ 14. It would bother me to sleep in a nice hotel room if I knew that a man had died of a heart attack in that room the night before.

How disgusting would you find each of the following experiences? Please write a number (0-4) to indicate your answer:

0 = Not disgusting at all

1 = Slightly disgusting

2 = Moderately disgusting

3 = Very disgusting

4 = Extremely disgusting

- ____ 15. You see maggots on a piece of meat in an outdoor garbage pail.
- ____ 16. You see a person eating an apple with a knife and fork
- ____ 17. While you are walking through a tunnel under a railroad track, you smell urine.
- ____ 18. You take a sip of soda, and then realize that you drank from the glass that an acquaintance of yours had been drinking from.
- ____ 19. Your friend's pet cat dies, and you have to pick up the dead body with your bare hands.
- ____ 20. You see someone put ketchup on vanilla ice cream, and eat it.
- ____ 21. You see a man with his intestines exposed after an accident.
- ____ 22. You discover that a friend of yours changes underwear only once a week.
- ____ 23. A friend offers you a piece of chocolate shaped like dog-doo.
- ____ 24. You accidentally touch the ashes of a person who has been cremated.
- ____ 25. You are about to drink a glass of milk when you smell that it is spoiled.
- ____ 26. As part of a sex education class, you are required to inflate a new unlubricated condom, using your mouth.
- ____ 27. You are walking barefoot on concrete, and you step on an earthworm.

The DS-R (Disgust Scale-Revised), Haidt, McCauley, & Rozin, 1994; Modified by Olatunji et al., in press. To calculate your score: First, put an X through your responses to items 12 and 16 (these items don't count). Then "reverse" your score on items 1, 6, and 10 by subtracting what you wrote from the number 4, and write those numbers in the margin. Finally, add up your responses to all 25 items (using your "reversed" scores on 1, 6, and 10). The total will be a number between 0-100. For more information see: <http://people.virginia.edu/~jdh6n/disgustscale.html>

Appendix I: Main Research Project: Generalised Anxiety Disorder Assessment (GAD-7)

Name:

Date:

Over the <u>last 2 weeks</u> , how often have you been bothered by the following problems? (Use “✓” to indicate your answer”	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Column totals ____ + ____ + ____ + ____

= **Total Score** ____

From the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission

Appendix J: Main Research Project: Patient Health Questionnaire (PHQ-9)

Name:

Date:

Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems? (Use “✓” to indicate your answer”	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

Column totals ____ + ____ + ____ + ____

= **Total Score** ____

From the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues. For research information, contact Dr. Spitzer at rls8@columbia.edu. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission.

Appendix K: Main Research Project: Self-Disgust & Perceived Other-Disgust Measure

Self-disgust

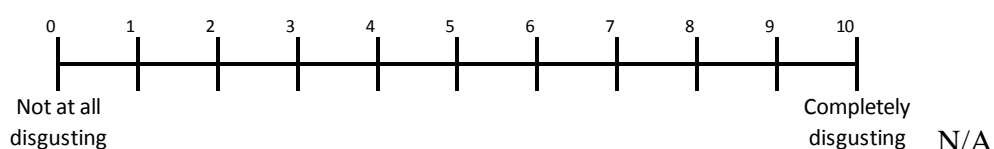
Name:

Date:

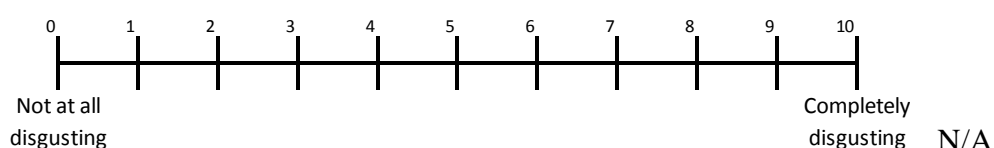
When people are physically less able (perhaps due to disability or aging) they sometimes need help with some of their everyday activities, such as help with eating or help to get washed or dressed. Some people do not mind this at all, some people may feel shy or embarrassed, while others may feel like they are ‘disgusting’.

Please read the following questions carefully and indicate on each scale how you have felt over the **past week**. If a question does not apply to you because you do not need help with that activity, please select ‘N/A’ (Not Applicable).

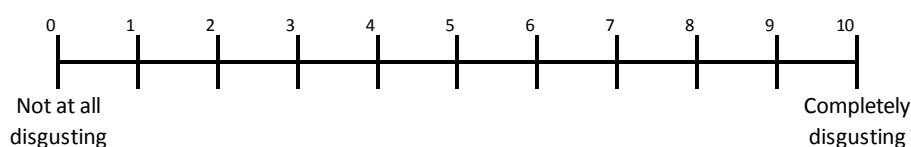
1. Deep-down, how do you feel when **other people have to help you to eat?**



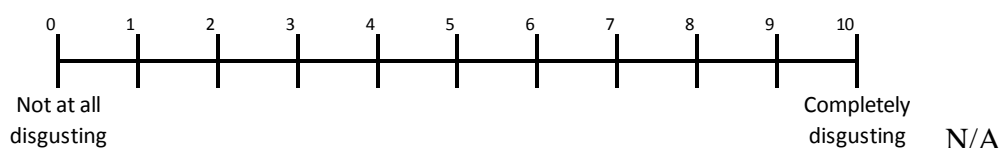
2. Deep-down, how do you feel when **other people have to change your wound dressings?**



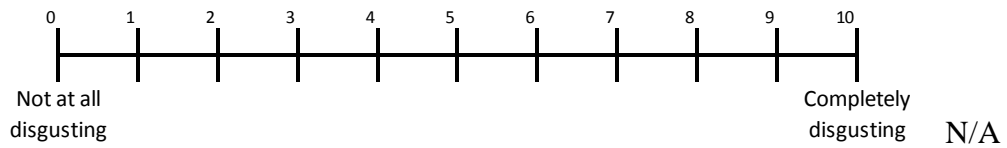
3. Deep-down, how do you feel when **you look at yourself?**



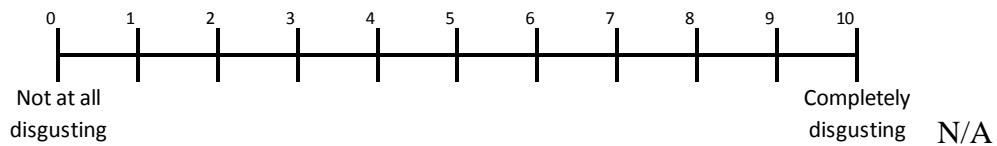
4. Deep-down, how do you feel when other **people have to help you to get dressed?**



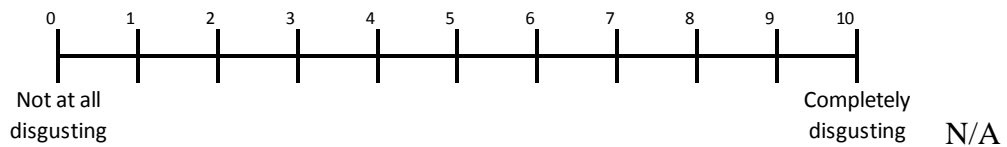
5. Deep-down, how do you feel when **you're incontinent?**



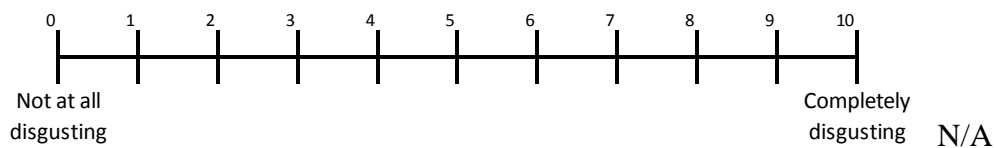
6. Deep-down, how do you feel when **other people have to help you to wash?**



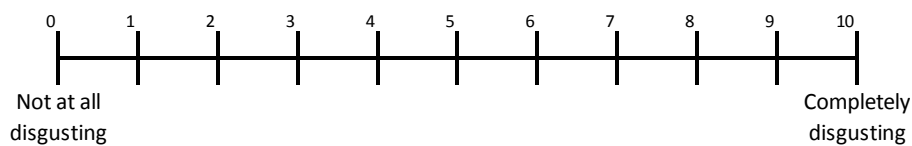
7. Deep-down, how do you feel when **other people have to help you to use the toilet?**



8. Deep-down, how do you feel when **you are not able to control your bodily functions?**



9. Deep-down, how do you feel about **yourself more generally?**



Perceived other-disgust

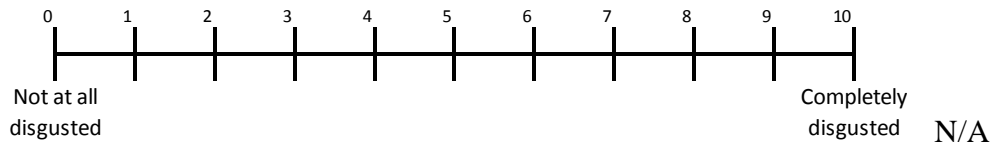
Name:

Date:

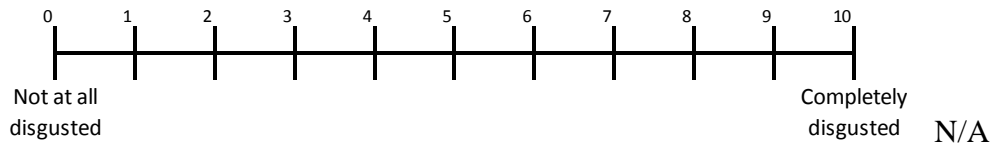
When people are physically less able (perhaps due to disability or aging) they sometimes need help with some of their everyday activities, such as help with eating or help to get washed or dressed. Some people do not mind this at all, some people may feel shy or embarrassed, while others may feel like they are 'disgusting'.

Please read the following questions carefully and indicate on each scale how you think **other people** have felt about you over the **past week**. If a question does not apply to you because you do not need help with that activity, please select 'N/A' (Not Applicable).

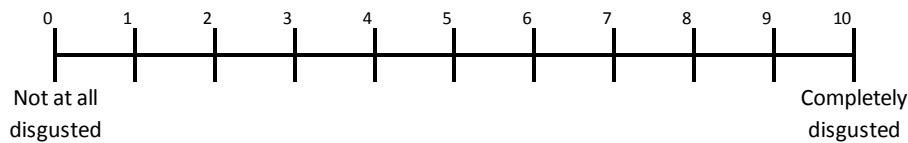
1. Deep-down, how do you think **other people** feel when they have to **help you to eat**?



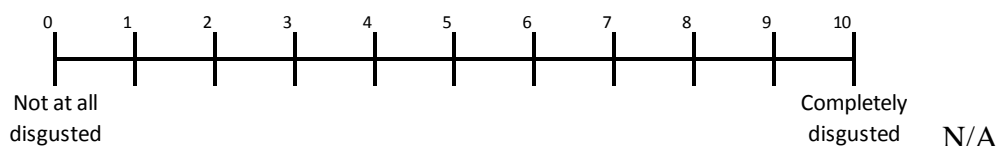
2. Deep-down, how do you think **other people** feel when they have to **change your wound dressings**?



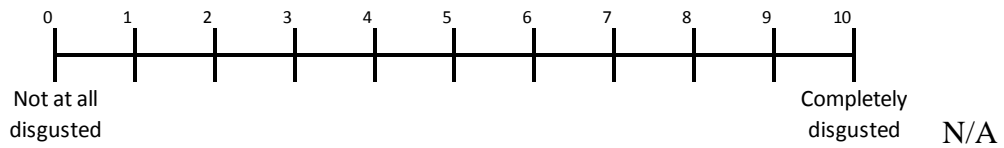
3. Deep-down, how do you think **other people** feel when they **look at you**?



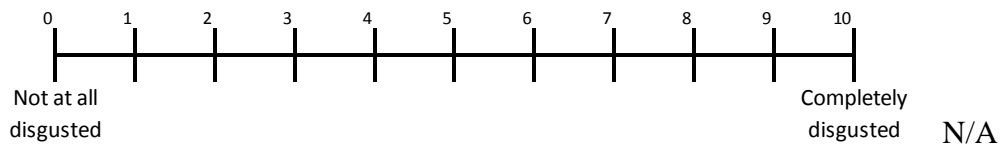
4. Deep-down, how do you think **other people** feel when they have to **help you to get dressed**?



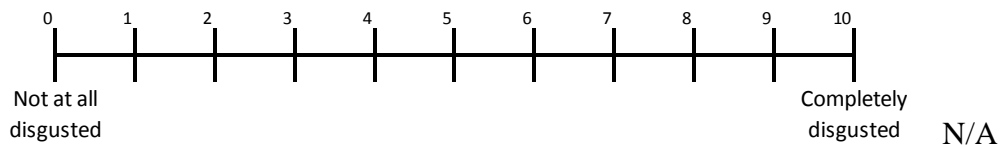
5. Deep-down, how do you think **other people** feel when you're **incontinent**?



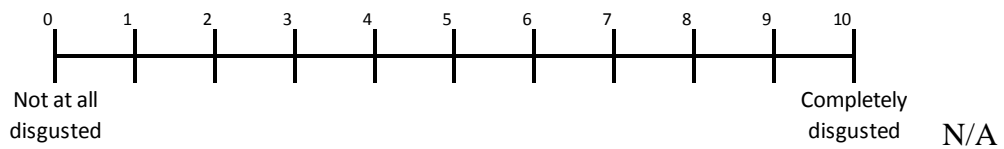
6. Deep-down, how do you think **other people** feel when they have to **help you to wash**?



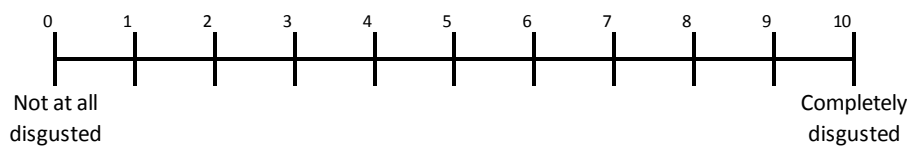
7. Deep-down, how do you think **other people** feel when they have to **help you to use the toilet**?



8. Deep-down, how do you think **other people** feel when you are **not able to control your bodily functions**?



9. Deep-down, how do you think **other people** feel about **you more generally**?



Appendix L: Main Research Project: Semi-structured interview schedule

1. "You said you feel disgusting when [e.g. someone is helping you to have a bath], do you always feel this way or are there times when you don't?" "If there are times when you don't, what do you think is different about those times?" (staff members - gender, familiarity, etc., time of day, underlying mood, etc.)
2. "How distressing to you are these feelings of being disgusting?" "Have you noticed whether you feel this more or less strongly over time?"
3. "Are these feelings something you ever discuss with other people?" (residents, staff, family, etc.). "If you do discuss these feelings, what do the effects of the conversations tend to be?" (helpful, unhelpful, reassuring, anxiety provoking, etc.)
4. "Are you able to say what kinds of thoughts you have in your head on those occasions when you do feel disgusting while [being helped to have a bath]?" "Do the feelings of being disgusting make you behave in certain ways?" (more reluctance, trying to hide body parts, etc.)
5. "Is there anything else you would like to add that we have not spoken about?"